“THAT WON’T HELP THE MEATBALLS”:

HEALTH CARE PROVIDERS’ PERCEPTIONS OF EATING, DRINKING, AND FEEDING AS HUMAN EXPERIENCES

by

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ABSTRACT

Background

Eating, drinking, and feeding are individual acts signaling our values, our identity, our cultural alignment, and care giving. Humans need oxygen, a system to transport oxygen, and fuel (food and drink), but only with the last of these do we choose what, where and with whom. Swallowing difficulties (dysphagia) affect nine million adults in the United States. Health care providers report more discomfort with dysphagia decisions than other clinical interventions. Feeding is a unique form of clinical care because providers live in both worlds: eating, drinking and feeding as fundamentally and culturally part of 1) human experience and 2) clinical process.

Aim

To explore health care providers’ personal and professional attitudes to eating, drinking, and feeding focusing on the incongruities between the two perspectives.

Methods

Two focus groups occurred with speech-language pathologists (SLPs) (total n=15) from rehabilitation settings and two groups with non-SLP front line providers (total n=15) from an urban health care network. Participants considered: 1) eating/drinking/feeding as a) a human

experience, and b) a biomechanical task in dysphagia care, and 2) why health care providers may deviate from practice guidelines. Dialogue was audio recorded, transcribed and studied using Thematic Analysis.

Results

A list of 33 codes gave rise to 8 themes: we eat and drink for health and life; meanings of food and feeding; nutrition/hydration versus food/drink; reasons for practice patterns; professional collaboration; patient control; economic concerns; improving things. Participants voiced concern that a) patients lose control over a highly meaningful life process, and b) health care providers do not recognize their role in this problem. Participants expressed inner turmoil with feeding interventions/decisions.

Bioethical Significance

Dysphagia intervention uniquely challenges and distresses people making decisions. Health care providers aim to do good but the definition of what "good" is should be broadened and addressed earlier in training. The telos (purpose) of eating and feeding is much more than the techne (doing) of medically framed nutrition. Addressing providers' distress could reduce patient/family angst and support informed consent because more appropriate questions can be asked and clearer information provided, especially valuable in situations when caregivers have to make decisions.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREFACE AND ACKNOWLEDGMENTS

This work is the product of a team: from design to completion, with many players. Clinical research strives to improve life but without volunteer participants we could not perform our work. My sincere thanks go to all those people who shared their thoughts and feelings so honestly on what it means to eat, drink, feed and care for others.

To my own students who may never read this: continue to mull on things, ask questions, and know that each time you swear never to go back to school it may still happen and you'll wake up in a class full of people whose words you don't understand, whose arguments you can't follow, but whose worlds you *will* explore and bring back little gems to help our patients.

To Megan Ballantyne for support with the practicalities of focus groups and hours of transcript and coding review – thank you.

To my friends for stifling the yawns so well as I expound on my latest cunning as a turnip plan - particularly Judy Navratil – we made it!

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To my supervisory team Daniel Hall and Rollin Wright for stretching their brains almost as much as I did mine, led by my gracious committee chair Martha Terry – go teach 'em to ***knit***.

Why: twelve years on from completing a swallowology PhD the combination of being a swallowologist and passionate foodie is my drive to continue work in the field of dysphagia. These words mean the same to me today as they did then. For what is life without the pleasure of eating? More so what do we do to patients, families and caregivers when we disrupt the human experience and symbolic ties encoded in the act of feeding?

> *"If we could give every individual the right amount of nourishment and exercise, not too little and not too much, we would have found the safest way to health."*
>
> Hippocrates (460-377. B.C.)

> *"The joys of the table belong equally to all ages, conditions, countries and times; they mix with all other pleasures, and remain the last to console us for their loss."*
>
> The Physiology of Taste (1825), Jean-Anthelme Brillat-Savarin

> *"I feed therefore I am"*
>
> Paula Leslie (1966 and still learning)

And cautionary note:

> *"Statistics show that of those who contract the habit of eating, very few survive."*
>
> George Bernard Shaw (1856-1950)

Nomenclature: the term health care provider is used to cover clinical professionals, rehabilitation staff, aides and others who support patients as part of their job. The term caregiver refers to family or other unpaid people involved in the care of a person with an eating, drinking, or swallowing impairment.

For clarity except in the verbatim focus group quotes, male pronouns such as he/him/his will be used when discussing a patient or client. Female pronouns such as she/her/hers will be used when discussing the health care provider or family caregiver.

In the Results' Chapter the data (quotes from the focus groups) are presented to support the themes. Sections of dialogue may include several speakers and the use of a dash (-) shows a change of speaker. A new section of dialogue is marked by a line space.

1.0 INTRODUCTION

Breathing, circulation, eating and drinking are all requirements for life and yet it is only with the last of these that humans have a choice over what, when and with whom. And what a weighty choice this is. Ingredients, preparation methods, serving approaches, are the focus of community and divide across nations and families. Starting from this perspective it is not hard to see why the issue of food and drink might suffer from even more contention in health care than the provision of a breathing system or something as basic as pain relief. Yet health care providers (and to a lesser extent patients and families) rarely show an understanding of this and treat the provision of food and drink as a biomechanical process once a person is in a health care facility or even at home but with a condition impacting eating and drinking in some way.

Food and drink are so basic to our existence, to our individuality, and to our social identity that we rarely stop to think about how we eat and drink until something goes wrong. Problems may arise for many reasons such as minor dental work when it simply hurts to eat, when the gastrointestinal tract cannot process the nutrients that the body needs, or when our mental processes are fading and we do not recognize the round, green ball as an apple, let alone that it requires chewing and swallowing. When conditions are terminal there comes a time when the provision of food and drink becomes more burdensome than beneficial but to let go of this act is deeply distressing for most people.

1.1 CONCEPT

Let us consider a clinical case: an elderly patient lay close to death, perhaps only a few days left. Close family surrounded the bed continuously and more relatives were on the way. All had agreed that “heroic measures” such as a ventilator to provide artificial breathing, and cardiopulmonary resuscitation to shock the heart back into action if it stopped, would be inappropriate. The clinical team was then asked to maintain the feeding tube which was unusual because the family clearly demonstrated that they understood the feeding tube was not providing any benefit and may have been causing unnecessary burden to their loved one. The family agreed to reduce what was in the “feed” to a solution with very few calories so it was not providing anything near what was needed for nutrition. But they begged to please keep the tube in place until other relatives arrived.

The family reported the importance of the other relatives seeing that their loved one was being fed. They had come to terms with losing their relative but the appearance of trying to feed was crucial. Families often find it easier to decide against breathing and heart support than to sanction no further feeding: “Deciding to stop or start nutrition and hydration - feeding tubes and IV fluids - can be an especially troubling decision. Nourishing another person seems like the most basic and humane option.” (Frontline, 2010, Nutrition and Hydration, para. 1). Initially the clinical team could not understand the family’s seemingly incongruent position.

Clinical research is starting to address how the patients themselves feel when they cannot eat and drink normally. This might require feeding tubes (parenteral nutrition and/or hydration) or a change in the nature (consistency modification) or quantity of food/drink consumed. Health care providers are often at odds with families who want to continue feeding a loved one when it is physiologically futile, or with patients who will not follow the recommended safest altered

diets. Despite the frequency of this contention being voiced by health care providers there is little understanding of why this topic is so problematic. There is little information on how the feeder feels about the change in situation for a loved one. Health care providers involved with people who have eating and drinking problems might be burdened unusually from two directions. With food and drink we have health care providers with a duty to do good and prevent harm; thus, when modified diets or alternative nutrition and hydration are required (or best stopped) they must push that agenda. At the same time health care providers are humans brought up in societies with strong thoughts on what food and drink mean, what they symbolize, and how the act of feeding is about the transference of more than mere nutrients.

1.2 OVERALL QUESTION

The ubiquitous nature of the medical intervention (feeding) may impact awareness of the contentiousness and deep feelings in this clinical area. We have mountains of research evidence about how to keep blood pressure under control in a host of conditions and circumstances, about the genetic code that links syndromes, about the immune suppression and surgical requirements for complex organ transplantation. With something as commonplace as feeding there is far less clinical understanding of what people think and why there is still such contention between the clinical and patient worlds.

This project explores the perceptions of eating and drinking as a human experience among people who have a foot in both camps: that of health care provider and human being. What do these people think about why we eat and drink? What comes to mind when we think of nutrition and hydration (medical terms)? And why do we still push clinical practices around

eating and drinking that evidence is showing do not help the conditions we are trying to work with?

1.3 APPROACH

Live interactions allow for exploration, clarification and correction of topics and language. Focus groups of invested participants are generally less confrontational than one to one interviews. Participants may choose whether to contribute to the discussion without the burden of being the only information source. Focus groups also allow for generation of ideas as a thought is sparked in one mind when hearing another's take on a topic. Thus, focus groups are an ideal medium with which to engage people and generate data on what *people think* about a topic. This information can be used immediately to address issues and may also be foundational in the design of further studies including additional focus groups, surveys, and cohort comparison work.

In this study focus groups were comprised of health care providers who work with adults with swallowing/eating/drinking problems. Two populations were sampled: speech-language pathologists (SLPs) and front line providers (FLPs). SLPs have within their scope of practice the assessment and management of swallowing disorders as well as the more familiar *speech and language* issues. SLPs issue recommendations about the safest way to eat or drink but are rarely involved in the day to day feeding of patients. FLPs in this study are deemed those who do have frequent contact with patients either weekly such as dietitians or daily such as health care aides and have a role to support patients at mealtimes.

2.0 BACKGROUND

Food and drink, eating, drinking and swallowing are so ubiquitous that we rarely spare a thought for what they mean. Food is not just fuel for the body (Barthes, 2013; Bourdieu, 2013). Food is a symbol of power, status, love and death. The breaking of bread together is a sign of communality across many cultures (Barthes, 2013; Bourdieu, 2013; Mintz, 1996; Wilk, 1999). Food is subject to worship and taboo (Harris, 2013; Lévi-Strauss, 1970). The act of feeding, the creation, provision and organizing of food and meals, is something much more meaningful to humans than just refueling. The act of feeding varies with context and may be representative of care and control, identity and gender role.

In the clinical world, we attend to food and drink because they are essential for life. Meaning and roles of food/feeding are rarely the focus of health care. Intervention in this area is perhaps unique in health care because it is the only life essential process that is also central to our human-ness, identity and community. How and why do things go wrong with feeding and what do we do to address them are crucial areas to understand but so too are the consequences of intervention particularly the hidden ones. When the person responsible for feeding the other can no longer do so for reasons outside of their control there may be considerable impact on the relationship.

2.1 FOOD IS DIFFERENT

Consider the Hagen women of Papua New Guinea and how they approach recognizing the loss to a mother when her daughter gets married. Customary gifts acknowledge this loss as the bride joins the new family. Pigs are a highly prized part of the Hagen world, and at a wedding they are given from family to family. The most prized pig will be offered from the groom's family to the bride's mother. This pig has a special name, "the mam peng kng, 'mother head pig' " (Strathern, 2012, p. 7) in recognition of this most special of gifts and is destined for the bride's mother alone not the whole family. The pig is presented live and the bride's mother is considered to eat the pig at this moment rather than when she might consume the flesh later. The groom's family feed the bride's mother with the work they put into growing the pig, in acknowledgement that her family line is now ended (dies).

The Hagen example shows how the transference of food is central to a life transition. The pig is not needed to feed a starving mother, and if she were starving there are other much less energy and time intensive ways to feed someone. It is not acceptable to simply go and buy a pig. But the pig is food and humans need food. They also need oxygen and a system to transport nutrients and oxygen around the body but there are no different symbolic color schemes for ventilators or air with a certain proportion of oxygen reserved only for birthdays and weddings. Food is essential to life but it is completely different to other life sustaining requirements.

In a work entitled *"Eating (and feeding)"* Strathern considers the eater and the eaten with examples of a human consuming an apple and then another deceased human (Strathern, 2012). Eaters have some degree of control over the thing that is eaten, for example choosing what to eat and putting it in the mouth. Eaters do not have control over how the body processes the material. The manner in which we eat and feed others and what we choose to eat/feed, expresses many

things dependent upon context and is a definite action. Eating is about the totality of consumption not just random placing of food into the mouth and so feeding is likewise. Strathern challenges the historical Western view of human agency as being founded in cognition (I think, therefore I am). She suggests that we consider the what if in terms of eating: “Imagine that it is not how one is or what one has that delineates subjectivity, but how and what one eats.” (Strathern, 2012, p. 2). Perhaps humans are humans because of this conscious consideration of what/how to eat that other animals do not do.

2.2 WHAT DOES IT MEAN TO FEED?

Feeding work is the term used to encompass the activities that result in a meal (Counihan & Van Esterik, 2013). This requires much more than just cooking food items and serving them to someone. Planning meals requires knowledge of what is in the kitchen cupboards, what must be bought, what goes with what in terms of taste and nutrition, where to buy products and financial management.

Along with this considerable behind-the-scenes work is the aspect of emotional management or emotion work. Knowing the preferences of friends and family members and what symbolism they attach to certain foods is something most people process even at an unconscious level: *the Thanksgiving table is not complete without Great Aunt Mae’s pickled cabbage*. Rarely is such thinking demanded of a chef in a restaurant or a health care provider.

Perhaps we have an iceberg analogy: what we see as the product (the meal) is only a small proportion of what is provided, transferred and demanded when a person acts to feed another. If so this may be a contributor to the tension in situations where the usual act of feeding

is altered or constrained. Or to put it simply: how do I encompass these many facets of my role as the feeder if you remove everything but the (bag of) nutrients?

2.3 WHEN THINGS GO WRONG

The swallow is a beautifully coordinated dance of cognitive processes, muscle movements, breath holding and valve sequencing. As humans evolved they worked well until they moved to upright motion and started to talk. Then the physiology changed and the tiny tube containing the entrance to the airway AND the entrance to the food pipe aligned themselves for a disaster that can only be averted by this amazing physiological dance that shuts the entrance to the airway, pulls the pharynx up, opens a set of valves, propels food from the mouth to the esophagus and opens everything up again so we can breathe. All of this takes place in under a second and we do it thousands of times a day. Until something goes wrong.

Dysphagia is defined as a difficulty with eating and drinking, specifically in maneuvering food from the mouth to the stomach (broadly the process of swallowing). Dysphagia has various causes including neurological damage (stroke, head injury), progressive diseases (amyotrophic lateral sclerosis, Alzheimer's disease), cancer (head and neck, brain), iatrogenic consequences and side effects of treatment (radiotherapy, surgery), trauma (gunshot injury, unsuccessful hanging attempts), and is a side effect of many medications (Jones & Rosenbek, 2010). The breakdown can be at a mechanical level such as altered anatomy or physiology, or at a programming level such as in damaged cortical processes (Logemann, 1983). Although it is also possible to experience conditions such as psychogenic dysphagia and anorexia nervosa, these conditions are beyond the scope of this research study.

In 2012 the United States National Health Interview Survey recorded that one in 25 adults reported some form of swallowing problem totaling an estimated nine million people, the equivalent of the population of the entire State of New Jersey, of whom only a small proportion ever sought professional help (Bhattacharyya, 2014). In a United Kingdom study of community dwelling elders (69-98 years) dysphagia symptoms were prevalent in nearly one in nine people who were otherwise living independently (Holland et al., 2011). The effect of dysphagia on health care systems is considerable with increased length of hospital stay, morbidity and mortality, all of which are compounded in the elderly population (>75years of age) (Miller & Patterson, 2014).

Health care provision for people with difficulty swallowing tends to focus on the medical need to maintain adequate nutrition and hydration. The volumes of various blood/body fluid components are monitored, body measurements of fat and muscle are noted, together with the amount of food/fluid intake. For some patients oral intake will require supplementation which might be normal food but higher calorie/vitamin supplements. When a person cannot maintain adequate nutrition/hydration orally, supplementation may be considered via a feeding tube into the gut or directly into the bloodstream in order to improve nutritional reserves.

Dysphagia is rarely an all or nothing condition. Many patients have difficulty with certain consistencies such as hard or flaky foods, or normal liquids, because they run quickly through the mouth and enter the throat before someone is ready to swallow (Logemann, 1983). This results in the familiar sensation of material going the wrong way, and in a healthy person the offending substance is coughed out before it gets to the lungs. We also constantly swallow our own saliva and an impairment in the ability to swallow results in our own secretions building up in the throat and entering the lungs which can lead to problems especially if the mouth is not

cleaned regularly to keep the bacterial load in check. Treatments for dysphagia usually involve either altering the consistency of food such as making it smoother or thicker, and/or restricting which food or drink a person may have, and/or using tubes to supplement/replace oral intake.

Medical practice has reduced difficulties with swallowing to the mechanistic description just provided, but eating and drinking are profoundly human acts: they are inherent to our very human-ness and have to do with "care giving" far more than merely fueling a body (Modi, Velde, & Gessert, 2010). All cultures across the ages have rituals related to, and preferences regarding, types of food/drink, abstinence and feasting. Life transitions usually involve food and drink: welcoming members to a new community, birth, marriage or just geographical relocation. In the clinical world these other components of eating and drinking are rarely attended to.

Until relatively recently the focus was on the critical medical need for nutrition and hydration and not how people felt about the condition or the treatment. Recent work with different patient populations has demonstrated that the impact of an eating/drinking/swallowing problem affects many areas of life for both the patient and their family. People with head and neck cancer are a relatively young population who can discuss what they feel about issues such as having to adapt how food is prepared/served and the impact on social life of limited menu options at different restaurants. Emotions including embarrassment and fear are commonly described (Ganzer, Rothpletz-Puglia, Byham-Gray, Murphy, & Touger-Decker, 2015). The same themes appear in people with neurological or other conditions resulting in dysphagia such as Parkinson's disease (Plowman-Prine et al., 2009) and amyotrophic lateral sclerosis (Sterling, Axline, & Ragland, 2013). Of note is that many people with swallow problems do not think that anything can be done to help them (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002).

Emerging evidence shows that families are deeply affected by the other roles of food and feeding. In Chinese society eating ability signals health. In a study of people with terminal cancer caregivers reported a double loss: that of their loved one and of their own role as the feeder and provider of nourishment (Bell, Lee, & Ristovski-Slijepcevic, 2009). The parental duty to feed a child was reported not to be satisfied by merely providing nutrients through a feeding tube (Petersen, Kedia, Davis, Newman, & Temple, 2006). Reactions to feeding problems can be dramatic such as families not eating together or even spouses experiencing significant weight loss because they felt so bad about eating in front of their loved one (Walker, 2005).

2.4 TECHNICALLY IT IS JUST ANOTHER TREATMENT

The uniqueness of eating and drinking as a biological process that must be managed in the clinical setting is mirrored in the way health care providers feel about the withdrawal of technological support. Christakis and Asch (1993) surveyed 862 attending physicians affiliated with a United States university medical department and from all subspecialties of medicine, and 481 (56%) responses were received (Christakis & Asch, 1993). The survey tool contained questions regarding demographic characteristics of the physicians and several case vignettes. In all cases:

> *the patient was terminally ill and comatose, had clearly expressed in advance a desire for life support to be withdrawn under these conditions, and the family agreed with that decision. The decision to withdraw life support had already been made (Christakis & Asch, 1993, p. 644).*

The physicians were then asked to rank their discomfort with the withdrawal of each of the options for life support. Physicians reported the greatest discomfort with the removal of tube

feedings (mean rank 5.42) and intravenous fluids (mean rank 6.35), compared with the removal of blood products (mean rank 3.27) or mechanical ventilation (mean rank 5.27) and the rankings were unlikely to be random ($p < 0.0001$) (Christakis & Asch, 1993).

Literature on life-sustaining interventions shows considerable variation in the order of withdrawal(van Beinum et al., 2015). One study recorded that dialysis, and artificial nutrition and hydration were withdrawn before vasopressors (Gerstel, Engelberg, Koepsell, & Curtis, 2008). Closer review of the Gerstel et al. study (2008) shows that there was a significant difference as recorded in the chart in terms of the cessation of drawing lab values and ventilation as compared to dialysis, hydration, tube feeding, and the use of vasopressors, but that there was no significant difference in order of these last three (dialysis being withdrawn first). Physician discomfort is rarely recorded in medical charts and so Gerstel et al. (2008) fail to get at physician discomfort with scenarios as with the Christakis and Asch (1993) work.

Evidence has not been published to date as to why health care providers find decisions around nutrition/hydration more disturbing than other interventions which are equally important to health and life. A health care provider's personal belief system is likely to play a role with factors such as religion possibly influencing clinical recommendations. In one United States study there was a clear association between religion and recommendation to withhold or withdraw artificial hydration and nutrition with Jews and Muslims significantly more likely to oppose the withholding, Muslims even more so with the withdrawing, and the least religious were less likely to oppose either (Wolenberg, Yoon, Rasinski, & Curlin, 2013). A recent paper in *The Lancet* asked experts from around the world how the decision is made to withdraw life sustaining interventions and there is wide variety in legal stance, family involvement, and timing of such decisions (J. Morgan, 2015).

Food and drink gradually morphed into a biomedical product and procedure over the last century or so (Bergstresser & Castellanos, 2015). In western medico-legal cultures (the United States in particular) there was a move to clearly delineate between a basic right and a medical treatment that can be started or stopped (Casarett, Kapo, & Caplan, 2005). The activity of eating and drinking is an essentially human act, which gets compromised when one needs these things but cannot have them without medical aid. To say that artificial nutrition/hydration is purely a process may be legally defensible but that does not alter how people think about the act. From requiring all nutrition and hydration via a tube, to all food must be soft and liquids thickened, to a low sodium diet, may be perceived by people as a continuum, which contrasts with the medico-legal position with a clearer cutoff (Casarett et al., 2005). Despite health care providers being trained and educated about nutrition and hydration, they were first and foremost members of a human social group who ate and drank.

2.5 SPEECH-LANGUAGE PATHOLOGY

Swallowing impairment is anatomically divided for the purposes of intervention. Oropharyngeal dysphagia refers to problems with feeding and swallowing that is the process up until food or drink enters the esophagus (Leslie, Carding, & Wilson, 2003). Esophageal dysphagia refers to problems mainly in the esophagus and entry to the stomach. There is obviously a degree of overlap because the process of eating, drinking and swallowing cannot be separated out into distinct phases. Broadly speaking otolaryngologists (ear, nose and throat) are the physicians responsible for the conditions that lead to oropharyngeal dysphagia but this may also fall under the purview of general practitioners, neurologists, head and neck surgeons. The speech-language

pathologist (SLP) is the health care provider most likely to focus on the detailed assessment, diagnosis, and treatment of the dysphagia. Intervention may also be the responsibility of occupational therapists, phoniatricians, physical therapists or dentists, depending where you are in the world (National Institute on Deafness and Other Communication Disorders, 2010).

SLPs are not immune to the peculiarities that occur with professionals who work with eating and drinking problems. Despite hard evidence that feeding tubes are not a panacea for all conditions SLPs display incongruency when asked about 1) the appropriateness of feeding tubes in advanced dementia, and then 2) whether they would still recommend feeding tubes for a patient for whom no advance instructions exist (Sharp & Shega, 2009). Sharp and Shega (2009) surveyed 1,050 medical setting SLPs and received 599 (57%) responses. The 599 were then checked against the inclusion criteria that they provide direct dysphagia services to people aged 65 years or older resulting in 326 final responses. The researchers found that although SLPs typically reported that it was inappropriate to provide tube feeding to patients with advanced dementia, they would go on to recommend tube feeding to these patients. This inconsistency of reported knowledge with recommendations is a form of incongruency.

Health care providers have been found to be overly restrictive in their recommendations in many areas of health care possibly based on the practice of defensive medicine. Defensive medicine occurs when health care providers take actions because of perceived fears rather than confirmed risks; this increases in societies that are generally more litigious such as the United States (Studdert et al., 2005). Health care providers are not always certain of the relative contributions of various “risk factors” but they are concerned about being held responsible for negative patient outcomes. In the field of speech-language pathology this may occur as one of the following:

- *positive action* such as unnecessary imaging or very conservatively interpreted studies (viewing them as pass/fail based on whether a patient aspirates rather than how much or how often);
- *avoidance behavior* such as insisting that patients who do not agree with conservative recommendations sign waivers purporting to absolve the SLP of responsibility, and then discontinuing efforts to manage the swallowing impairment or the associated concerns (e.g., oral hygiene).

Managing risk is a duty of any health care provider; the difficulty is when the potential costs (and benefits) are not certain thus making the risk analysis nebulous. This is also preference sensitive because the analysis is peculiar to each patient based on what their risk tolerance is and what they are particularly hoping to achieve or avoid. Consider the example of linking aspiration to pneumonia. Aspiration occurs when material gets into the lungs that should not be there. There is a logic to connecting aspiration to poor outcomes but there is little hard evidence to connect mere aspiration with say chest infections. There is evidence to show that bacteria entering the lungs result in poor outcomes but this is equally likely with chronic saliva aspiration as it is with periodic food or drink going the wrong way. The culture in the field of speech-language pathology was until very recently focused on avoiding aspiration at any cost. Thus, patients were put on restrictive or even non oral diets just in case material went into the lungs. The problem is that putting people on the most restrictive, i.e. non-oral, diet also leads to withholding of oral medications such as with medications to prevent seizure or treat parkinsonian symptoms. This may be as, or even more, dangerous than possible sequelae of aspiration. In one deeply distressing incident a daughter recalls the last hours of her mother's life:

> *Another aspect of Mother's case, which highlights aspects of decision-making in hospitals, was the absolute refusal by the hospital to allow her to have her seizure medication on the evening before this final seizure – that was the evening she had been admitted to hospital. I knew from experience that, without medication, she was prone to have seizures.*
> *The hospital was adamant she was not allowed to swallow anything because she might aspirate. There was no satisfactory response to queries about alternative methods of administering her medications (Tubridy, 2011, para. 11).*

Evidence has existed for some time that placing people on modified diets reduces intake and so increases the likelihood of dehydration or malnutrition (Westergren, Unosson, Ohlsson, Lorefält, & Hallberg, 2002; Wright, Cotter, Hickson, & Frost, 2005). Yet it took years before such data were considered compared to the possible, more remote threat of a chest problem following aspiration (about which no hard research evidence exists). This is like the psychological and social costs of clinician recommendations, such as maneuvers that make the patient too self-conscious to participate in social events (Ekberg et al., 2002; Westergren et al., 2002). This may be so significant in people's lives that patients and those closest to them experience social bereavement when activities of normal life such as communal meals or celebratory gatherings are no longer undertaken due to the problems with eating/drinking (Walker, 2005). This affects both the eater and the person(s) preparing meals and results in isolation and reduced social participation.

2.6 HEALTH CARE PROVIDER TENSION

Health care providers are focused on the possible physical consequences of a swallow problem even in light of evidence that does not support this. Until recently the psychological and social effects were less attended to than the physical even though they have physical connotations. It is

not just the person and his swallow that are affected by dysphagia but his social world and that of his family and caregivers. There is some evidence emerging on how patients view dysphagia, altered diets, and artificial nutrition and hydration. These people may be described as having the role of the feeder.

There are fewer data on those who have the role of the feeder, particularly those outside of the family such as health care staff in community or hospital settings. There is even less information about those health care providers involved in caring for patients during mealtimes rather than those diagnosing and recommending treatment. The hospital or care facility takes on the responsibility to feed those in its care. This is passed down to the individual staff member who feels pressure to ensure a patient is fed because of her role in the institution. An institution does not experience the emotion that an individual human caregiver feels. The human involved in the one to one engagement with a patient regarding food and drink experiences a sense of duty as an employee and the basic human drive to feed.

Humans show social status by what they eat and in the way it is eaten (Barthes, 2013; Bourdieu, 2013). These are deeply embedded aspects of identity. This bears much weight in modern multicultural societies where health care is typically provided by one culture with a specific model and yet serves many groups with individual representations about what and how to feed. The FLPs face the battles between the clinical world of nutrition and hydration and the human world of what the meal signifies and what it means to have choice in what you eat and drink.

At a practical level, it is important to know how those responsible for feeding address the recommendations regarding swallow problems with a patient. There is clear evidence that SLP recommendations are not followed (Chadwick, Jolliffe, & Goldbart, 2002; Colodny, 2005;

Crawford, Leslie, & Drinnan, 2007). The reasons for this are often grounded in practical common sense and include simply too many recommendations being issued, lack of understanding by the feeder of the rationale for an approach with a patient, adaptive devices not being available, and of course the pressure of productivity. Thus, the responsibility lies partly with those issuing the recommendations, with the institutional pressure on a feeder, and the feeder's knowledge.

Focusing on the feeder, for example, a certified nursing assistant or health care aide, traditional thinking was that if more education were provided about the swallow mechanics and why certain approaches are preferred, then recommendations would be followed (Chadwick et al., 2002). Practicing SLPs have continued to be dismayed and frustrated when, following their carefully crafted in-house training, they watch patients being fed with lack of regard to the recommendations for safer eating and drinking. This may be due to more than just the knowledge of biomechanics but a belief in what food and feeding are about. The purpose of eating food and feeding carry culturally-specific symbolism and values that one may argue are equally important to individuals. One study of certified nursing assistants in residential facilities identified two distinct belief sets regarding their roles with feeding: *social* feeders and *technical* feeders (Pelletier, 2005). The social feeders viewed the mealtime as a time to engage with the patient and to socialize. The technical feeders prioritized the need to ensure adequate consumption. The social feeders regarded the technical feeders as being pushy with feeding. The technical feeders viewed the social feeders as not trying hard enough. Both groups knew something about swallow problems and the importance of nutrition and hydration, they both genuinely cared for their patients, but they approached the act of feeding differently.

Health care providers involved with patients who have swallowing problems do not base all of their actions on what is practical (or practically limited) as seen in the above study. People approach recommendations and interventions in individual ways often based on experience. Despite education of swallowing disorders and the utility of intervention approaches now required at the graduate level there are greater misperceptions of some concepts such as gastrostomy feeding tubes not improving functional status, among students than among experienced practitioners who did not have such learning in graduate school (Corbin-Lewis, Sullivan, Murray, Leslie, & Morrey, 2012). This suggests that ongoing clinical learning and reflection is important to develop appropriate practice because not every clinical scenario can be examined and taught about in school and the complexity of the individual contributes to the tension felt by health care providers.

2.7 DECISIONS

Eating and drinking are central to the human experience. In the clinical world, we have reduced the complexity of a meal to a technological process of fueling the biological machine. This aspect of clinical care may be unusual in that it resides right at the boundary between two worlds. The meal and its associated markers of individuality, culture and community are quite unlike other facets of human health such as the need to breathe, move, or excrete with which there is no choice of when, where, or what (although there may be matters of cultural finesse). The experiences and language of eating and drinking signal specific things to humans as social beings. So patients and families thinking of the human experience may well be talking of different issues when they have to discuss the impaired swallow and the biomechanics of eating

and drinking. They will be viewing the topic from a different framework to the health care providers with terms meaning very different things to each side.

Complicating matters is that those health care providers grew up as social beings where “eating” and “drinking” were human experience but are now associated with a medical need. The loss of agency over a core aspect of a person’s identity may contribute to the discomfort in making decisions and abiding by others’ recommendations where food and drink morph into a medical intervention. One aspect of this change is that the patient as a person who feeds himself what and when he likes now becomes dependent on another for this action. Complicating the situation is the range of beliefs held by those involved of what constitutes food or drink, and what eating, drinking and the act of feeding represent. And finally how as a health care provider one must tread the line between medical need and human experience. These factors are relevant to many patients and health care providers because of the prevalence of eating/swallowing problems.

Ideally medical intervention follows a process of decision making including its appropriateness and acceptability to the people involved. Health care providers tend to believe in the recommendations that they make and there is often a common appreciation of why patients do or do not follow such advice. Aside from life or death decisions involving say feeding tubes, recommendations around eating/drinking, safe swallowing practices, and the act of feeding constitute the majority of queries and angst in SLP professional community discussions. Patients with conditions such as hypertension, also important for health, regularly do not lose weight, do not take medications as prescribed, do not take more exercise, as advised by their physicians and yet for example, the physicians do not report sleepless nights on the topic. A deeper understanding of what food, eating and feeding is needed to help patients, families and health

care providers with decisions. This study will focus on the act of feeding and the actors who must straddle the line dividing the health care provider charged with a duty to a patient and the human with a lifetime experiencing the pleasure, symbolism and importance of eating.

2.8 RESEARCH QUESTIONS

To date we lack information from the clinical community on the perception of the role of the feeder and the incongruence between clinical knowledge and recommendations in certain circumstances. We need to address health care providers' perceptions of nutrition/hydration as a physiological process as compared to the personal experience of eating/drinking. Using focus groups and semi-structured interviews, we will explore people's personal and professional attitudes about altered approaches to eating and drinking, paying attention to incongruities between the two perspectives. The specific aims are as follows:

Aim 1: to explore how health care providers perceive eating and drinking compared to the provision of nutrition/hydration.

Research Question 1: How do health care providers view the provision of nutrition/hydration in the clinical setting compared to how they view eating/drinking as a human experience?

Aim 2: to explore the incongruity between health care providers' knowledge of altered approaches to providing nutrition and hydration, and their recommendations regarding such approaches.

Research Question 2: What factors do health care providers identify as reasons for the discrepancy between clinical knowledge of an intervention compared to recommendations regarding that intervention in certain cases?

3.0 METHODS

For this study a focus group approach was used. Participants from certain populations were invited to attend a small group and asked questions in a semi-structured interview format (Krueger & Casey, 2009). The question script was developed in collaboration with peers, students, and health care providers prior to the main study (see Appendix A).

This study was supported in part through funding received from the SHRS Research Development Fund, School of Health and Rehabilitation Sciences, University of Pittsburgh. This covered the transcription services and some supply costs.

3.1 IRB PROCESS

The project met the requirements for an EXEMPT study under the category of *Tests, surveys, interviews or observation of pubic behavior* under section 45 CFR 46.101(b)(2) on December 8 2015 (see Appendix B). The University of Pittsburgh IRB reviewed the initial invitation letter/email, the final participant invitation letter/email(s), the Introductory Speech and interview question script. It is important to note that a study that is granted Exempt status is not subject to further IRB review thus changes in approach may be made without returning to the IRB for sanctioning unless the changes affect the regulatory requirements pertaining to the exemption. Another important feature of the Exempt status is that a written *consent to participate* form is not

required. Participants were provided with the study details and invited to attend a focus group. The introductory script clearly stated that people could leave at any time, that people could contribute or not to any question, and that material would be kept anonymous even if specific quotes were used.

3.2 FOCUS GROUPS

Focus group work gathers thoughts and concerns on a topic which can then be used to inform the design of further work including surveys, interviews, and alternative sample focus groups. Preliminary work is particularly important to ensure that terms and language are generated from the populations concerned rather than presumed by the researchers. This language can then be used in further work. Focus groups provide a structure that allows participants to remain silent on a topic if they prefer without the pressure in a one to one interview. Focus groups also create a situation where ideas cross pollinate and provide data that might not be revealed in individual interviews with the same participants (Krueger & Casey, 2009; Langer, 2007; Massey, 2011).

A homogeneous group of people are chosen specifically because they have something in common and they are invited to share thoughts on an issue or experience from their perspective. The transcripts of these discussions are examined and the research data are the participant quotes and the interpretation is acknowledged to be that of the researcher. Themes are identified by the researcher and the rationale for why a quote represents a theme must be transparent.

Strategies such as purposeful sampling may be used to ensure that the people who get to participate in the focus group represent the individuals that the project is focused on. So from the volunteer pool certain characteristics may be checked for such as gender, age, employment

background, workplace setting, relationships and geographical location. The characteristics are chosen to attempt to stratify the actual participants who are important to the topic under investigation. The final composition of the group will be limited to those who volunteer. It is also important to ensure that a group's participants are similar enough to feel free to speak in front of each other hence the separation of SLP and other FLPs in this study (D. L. Morgan, 1995).

The role and skills of the facilitator are fundamental quality indicators in focus group work (Langer, 2007). The facilitator is the instrument of data discovery and must be carefully prepared as with the focus group selection and script. Facilitators must be organized, able to create rapport quickly, able to monitor what has been covered, present in the moment and have half an eye on what still needs to be done, able to manage group dynamics, and able to sense when they must probe beneath apparently good but superficial issues (Krueger & Casey, 2009; Langer, 2007). The live nature of the focus group process includes information in direct response to planned questions and "inevitable digressions as participants shape and reframe questions" (Massey, 2011, p. 22).

3.3 INTERVIEW SCRIPT DEVELOPMENT

The interview script serves two purposes: first, it explains the nature of the study and group session to remind people why they are there; and second, it contains the semi-structured interview questions. The introductory part of the script follows a standard approach of information sharing and explaining the voluntary nature of contributions/participation. Practicalities are explained such as where the restrooms are and refreshment availability. The interview questions are unique to a focus group and are carefully worded and sequenced to

enable participants to provide information that suits the aim of the project: it is all in how you word the question.

For this study the questions were set up to establish thoughts from two perspectives. First participants were asked to think about eating and drinking in their role as a human being, in general in their own everyday lives. Then a mental shift was required to enable participants to think about the role of food and drink in health care or as it is more usually called *nutrition and hydration*. This section was introduced using the phrase "*put your professional hat on and think about your work with patients.*" As the four groups covered several different perspectives it was important to have one question that covered all possibilities. Specific scenarios may also be addressed which in this study was the question "*Research shows us that altering the consistency of food/drink results in people eating less, and feeding tubes do not help everyone, yet we still recommend these things. Why do you think professionals do this?*"

One result of a focus group is that inherent in the activity of talking about an issue people may generate ideas and actions to address it. Finishing the discussion on a positive/solution focused note rather than in the dark place of a problem is good practice. Thus the question "*In situations when we alter how people get food/drink, how could we improve the experience of the patients and their caretakers?*" Such an ending does not aim to fix the problem, only to guide people towards possible solutions that they generate themselves and may lead to action by the group members.

The final script and questions were discussed by the researcher [PL] with the thesis committee which included the thesis advisor (expert in focus group methods), a geriatrician and a general surgeon both of whom have relevant clinical experience and bioethics training. The

questions were also shared with colleagues within speech-language pathology with relevant experience but who would not be members of the focus groups.

3.4 PARTICIPANTS

This study was comprised of health care providers who work with patients who require some sort of altered diet or route of feeding, for example thickened liquids, soft diet, or tube feeding. The first population was SLPs who work in acute care hospitals, rehabilitation facilities, or home health services and who are responsible for assessing and/or treating adults with dysphagia. The samples from this population are referred to as **SLP Group Ia** and **Ib** (see Figure 1: Participant groups).

The second population was comprised of health care providers who work with people with dysphagia and are responsible for implementing SLP recommendations but who are not responsible for the assessment of such patients in terms of their swallow problems. This included health care aides/assistants, nurses and dietitians. The samples from this population are referred to as **FLPs Group IIa** and **IIb** (see Figure 1).

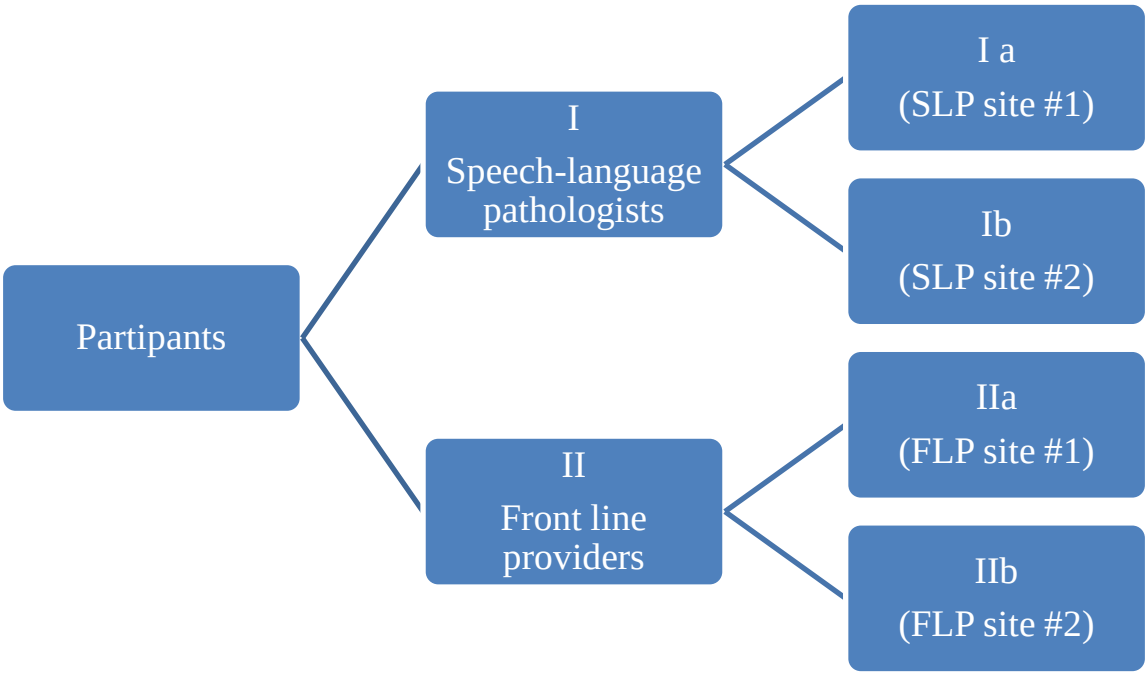

Figure 1: Participant groups

3.4.1 Recruitment

Participants in Group I were recruited from two American Speech-language Hearing State Associations in the spring of 2016. These meetings are the largest regional gatherings of SLPs and provide a reasonable potential volunteer pool of SLPs from the work settings of interest. Following invitations to speak at two State conferences the author [PL] asked if the focus groups might be run during the conferences. The Conference board for each State was approached with the outline of the study, the IRB "Exemption" judgment letter, and the email wording to be distributed to each State group's membership (see Appendix C).

Participants in Group II were recruited from an urban health care network. The patient population of this organization consists of people over 55 years of age and who have chronic

health needs but are able to live at home with support. This patient group has a high incidence of feeding difficulties due to age and co-morbid conditions. The organization has home health staff and day centers across several sites in a large metropolitan area where many patients come for activities and lunch so a large proportion of the health care staff are actively involved with dysphagia issues. The FLPs were required to have experience of or to be currently working with patients directly at mealtimes, where some sort of alteration has been made to the mode of delivery or consistency of food and drink.

The urban health care network organization kindly allowed the staff who participated in the study to do so during work hours. This enabled participants to attend who might otherwise have had difficulty attending after their work shifts due to second jobs, child care responsibilities or other demands. The organization enquired as to whether administrators/mangers might attend the groups in an effort to identify ways to improve care to their patient population. For this study the participant group was restricted to FLPs of any profession/level (except SLPs) who had regular contact with patients, and thus excluded administrators/managers.

Letters of invitation were written at a reading level of 6th grade following the recommendations of the University of Pittsburgh Institutional Review Board (University of Pittsburgh IRB, 2015). Contact was made via the conference/facility organizer/director explaining the nature of the study, and interested parties contacted Dr. Paula Leslie about participating. The letter was an email or hard copy letter depending on the facility's preference. The author [PL] did not have access to the email lists directly but used the conference/facility organizer/director as a gatekeeper. For the SLP groups emails explaining the study and inviting interested parties to contact the author [PL] were sent out three to four weeks before the conference and then one to two weeks. Individual SLPs were emailed or telephoned to respond

to requests for information. For the urban health care provider emails were sent out in mid spring for late spring/early summer meeting times. Two sites were offered by the organization with some staff attending from a sister site to achieve a reasonable number (six to twelve participants).

3.4.2 Sampling

From each population two groups were recruited each with six to 12 participants which resulted in a total of four focus groups. A sampling strategy was prepared to be used if the number of participants exceeded the number required for a group. This paid careful attention to characteristics of the volunteers to optimize the range of viewpoints such as clinical setting, employment role, years of experience, years of working with people with swallowing disorders, training in swallowing disorders, and gender (not possible in the SLP groups where the profession is 98% female). In practice all four focus groups comprised fewer than 12 participant volunteers and so the sampling strategy was not used.

The approach in this study was one of convenience sampling that is, to use established conferences/facilities because of access and relevant potential participants. One might argue that to randomly sample from a population who did not have an interest in the topic would be unethical as it would waste time and resources (Krueger & Casey, 2009).

3.5 ANALYSIS

A full coding approach was used because the concepts of food/drink as a human experience and what this represents are not well understood, are very personal, and may vary widely. Thus no

preconceived themes were defined before the analysis started. The data were investigated using thematic analysis. This is an approach that is often used but not always clearly defined or acknowledged (Braun & Clarke, 2006). Braun and Clarke (2006) urge researchers to be as diligent and robust in their application of this approach as they would with any other and describe the phases that are required:

- Getting familiar with the data which may include the transcription process itself
- Initial code generation working across the whole data set
- Theme identification across all the codes
- Theme review back to individual codes and the whole data set
- Refining theme definition and relating them to the overall story
- Producing the report linking pertinent examples with a narrative and existing literature on the topic, and relating this back to the research question

The focus group sessions were audio recorded using two Olympus ® VN-6200PC digital audio recorders placed apart on the tables that participants sat around. This was to ensure capture of all input particularly when using an oval table (provided by the setting and not under the control of the author [PL]).

Each main question had a number 1-8 which was marked in the transcripts. If unscripted questions had to be asked that pushed for exploration of an issue or clarification they were denoted as 1.1, 1.2 etc. and marked in the transcript. This allowed for tracking of responses to specific questions when the text was coded and analyzed for themes.

3.5.1 Familiarization with the data

All discussions were audio recorded, transcribed and coded. An original transcript of each session was kept together with the coded version. The author [PL] was the facilitator for each focus group and so familiarization began as the data were being generated. During the focus group session the author [PL] took notes to supplement the audio recording; a student took notes for three of the four groups. Notes were made when a person(s) reacted with facial expression to something, or there was group agreement, or any other reaction that might not be captured in the audio record.

The first focus group was transcribed by the author [PL]. Transcripts for groups 2, 3 and 4 were professionally transcribed using the TranscribeMe!® service. Each of the professionally produced transcripts were then checked by the author [PL]. This provided a second opportunity to review the data as each transcript was compared to its entire audio recording. All transcripts were checked again by a student who is learning about focus group methods with the author [PL]. Both recordings were reviewed for each focus group to ensure capture of as many data as possible. Occasionally in any recording some data will be inaudible and this was indicated in the transcripts. Where possible the author [PL] would ask for repetition of contributions. The author [PL] and the student compared session notes to the transcripts and added information as comments to the transcripts.

3.5.2 The approach to thematic coding and codebook development

When the transcripts were complete and had been double checked the coding began. The transcript for FG #1 was read first. Each time the author [PL] felt that a section of text (phrase/sentence/paragraph) indicated a theme a CODE was created and defined. The code might

apply to one quote or a conversation of several turns/speakers. A theme such as anger (code ANG) can be further specified e.g. anger at the disease (ANG_DIS) compared to anger at the care team (ANG_CARETEAM). Code descriptions/definitions need to be clear and concrete, broad enough to apply to all transcripts but narrow enough to avoid loss of detail (see Table 1).

Table 1: Example CODE, definition and illustrative quote

CODE	Definition	Quote
HISTORY	Relating to historical connections and transference across time (people, places)	*I have one like that, umm there was a salad that my mom always made. Her name was Mae [pseudonym] she's passed away now almost two years, but my whole family calls it Aunt Mae's salad so when umm, it's a seven layer salad, so every time when we have a family function I still make that and I say "I'm bringing Aunt Mae's salad" and everybody's excited because they remember my mom and you know it, it makes them happy, and then it makes me happy that they still want me to bring that. So umm you know then that's been passed down from my mom. I don't know where she got it from but she gave me the recipe and then now I carry that on so that's a big, a big deal for my family.*
LEGAL	Relating to malpractice, fear of blame for bad thing happening to patient	*I don't wanna kill them. That's my biggest concern. I don't want to cause them death. Or assist with that… because I don't wanna be blamed.*

During the reading of the first transcript the codes were reviewed and refined in an iterative manner. Each time a code was refined any previous use of it was reviewed. Each time a new code was created it was compared to other similar codes to avoid duplication and maintain clarity. The preliminary code book was then used with each transcript FG #2-4 in turn, again creating, refining and reviewing codes with any previous use. When the fourth transcript had been coded, the refined codebook was used to go through each transcript completely for a second time (see Appendix D). The codebook contains the definitions of each code such that a naïve reader could review a code description and assign a particular code to the same parts of the text as the original coder.

4.0 RESULTS

Four focus groups were conducted in the spring/early summer of 2016: two from American Speech-language Hearing State Associations (SLP Ia and SLP Ib) and two from an urban health care network (FLP IIa and FLP IIb).

Thirty-three codes were developed which may be broadly grouped into eight themes. As with the code definition these groupings are according to the perspective of the researcher [PL]. The codes, their definition and how they were grouped into themes can be seen in Appendix D Table 3 and Table 4. The themes relate to the following:

- Why we eat and drink – health and life
- The meanings of food and feeding
- Nutrition/hydration versus food/drink
- Reasons for practice patterns
- Professional collaboration
- Patient control
- Economic concerns
- Improving things

4.1 POPULATION DESCRIPTION

All participants were asked to complete a short survey during the group. All responses were voluntary, written free text with no names required. The questions asked for the SLPs: Age, Ethnicity, Gender, CCC-SLP (national certification for full clinical practice), Work with type of patient group (years?), Work in type of facility (years?), Member of Special Interest Group (SIG) 13 (swallowing), SIG 15 (gerontology), other SIG. The questions for the FLPs were: Age, Ethnicity, Gender, Work with type of patient group (years?), Work in type of facility (years?). All participants were asked to comment on *who does most of the cooking in your family?* (See Table 2)

Table 2: Focus group participant details

Focus group	**FG #1 SLP Ia**	**FG #2 SLP Ib**	**FG #3 FLP IIa**	**FG #4 FLP IIb**
Age median years (min – max)	42.5 (29-64)	53 (28-61)	41.5 (30-50)	38 (28-68)
Ethnicity (participant defined)	8 white / Caucasian	7 white / Caucasian	8 white / Caucasian	7 black / African American, 2 white
Gender	8 female	6 female, 1 male	7 female, 1 male	9 female
Patient type (duration years)	Adult (median 5, 4-32)	Adult (median 14, 3-29)	Adult* (median 7, 3-30)	Adult (median 11, 2-26)
Facility type	Acute/Rehab/ Developmental Center	Acute/Rehab/ Developmental center	Community center	Community center
SIG membership	13(two), 15(two), 4, 11	13(three), 15(one), 2, 10, 16, 18	-	-
Primary feeder at home	4 self, 3 spouse 1 other	1 self, 2 spouse, 4 missing	7 self, 1 spouse	6 self, 2 spouse, 1 other

** Group 3 did not complete the **duration with patient type** box but did put durations in the **facility type** box. These figures are used to show an approximate median and range of experience.*

All participants worked primarily with adults but several reported working with a range of patients currently or historically including school aged children and children/adults with intellectual impairment. Settings included schools, outpatient, residential group homes and home based services. The groups closely resembled one another in terms of median and range of years of experience. All groups had at least one person who was the primary feeder in their own home.

The most recent graduation date for both SLP groups was 2011, thus five years was the minimum length of experience indicating that there were no novice SLPs. The minimum duration reported of working with people with dysphagia was three years indicating a solid base of experience with the study topic. The FLPs had similar work history experiences.

4.2 WHY WE EAT AND DRINK – HEALTH AND LIFE

When asked why people eat and drink participants responded initially with concrete reasons such as hunger, for health, and survival. People eat when they are hungry because the body needs food (*food* was the term used more often but *nutrition* was also mentioned):

- *To stay alive.*
- *To survive.*
- *Did we say sustaining life (FG 4)?*

All groups raised the concept of simply eating for pleasure and occasionally for less positive reasons such as boredom or stress:

When we're sad from stress (FG 3).

One group looked deeper at the rehabilitation perspective. They discussed the lack of appreciation for the fundamentals of being adequately nourished and hydrated (and excretion, sleep and pain control) in order to undertake rehabilitation activities:

> *Physical therapy probably isn't gonna kill me… speech therapy potentially could. Or I don't have the nutrition and hydration to… participate in physical therapy. It's probably the foundation, when you think of you know, what things do you need to be able to do rehab, 'cause let's just… we're all are doing some level of rehab, right? That's what we hope we're doing, we hope we're not just… just satisfying end of life... but sometimes it turns out to be, ok this is what I'm gonna do, I'm gonna fight, fight, fight… well, I'm kinda stuck… because not everybody understands the foundation of nutrition and hydration as being… he can't perform in that PT and OT if he doesn't have that, you know, if he's not using the bathroom, in both directions… sleeping, having pain control, and eating and drinking (FG 1).*

Although many comments were specific to either eating or nutrition it was common for the biomechanical need to be included with psychosocial concepts in the same statement. This raises the question of what does the body need. Here is an example of how recognition of the physical need (of food/drink) for survival is also crucial for the other activities of a human life such as socialization and even the idea of being "present in life" however that might be defined:

> *It's just based on, sometimes too it's based on um cultural kinds of things. Just in general, er you know, religion to socialization um other things, happen to do like with nutrition just in general.…..…what the body strives for what it needs to survive, what it needs to process, needs to almost conduct those socialization kinds of tasks, to be present in life (FG 1).*

4.3 THE MEANING OF FOOD AND FEEDING

Food is fuel for the body but when asked why people eat and drink all groups moved quickly from the physical need to the associated meanings, sometimes within the same sentence as seen above. Links with family were prominent, both current interactions and memories of people past

or distant. Often a common dish such as a salad or a type of pizza was intimately associated with a person and bore meaning for the individual preparing the dish and those that will partake of it:

> *I have one like that, umm, there was a salad that my mom always made. Her name was Mae [pseudonym], she's passed away now almost two years, but my whole family calls it Aunt Mae's salad so when umm, it's a seven layer salad, so every time when we have a family function I still make that and I say "I'm bringing Aunt Mae's salad" and everybody's excited because they remember my mom and you know it, it makes them happy, and then it makes me happy that they still want me to bring that. So umm, you know then that's been passed down from my mom. I don't know where she got it from but she gave me the recipe and then now I carry that on so that's a big, a big deal for my family (FG 1).*

Imbuing a simple food stuff with meaning beyond its nutritive value raises expectations by those on the preparation and receiving ends: that the dish appears at certain events, that it is prepared by a certain person, that it is made to a specific recipe. The participants in this study were health care providers talking about how food was regarded by them personally as human beings before their clinical role. People may have very narrowly defined criteria for what makes some thing, the thing:

> *- Have you ever had the situation where somebody's like, "oh, I make like a vegetable pizza or I make a seven layer salad" and then when you look at it you're like… that's not… that's not what it is. [face pulling and others nod and smile] It's not like a judgment but you're like "what the heck is that?"*
> *- It is a judgment! [Laughs.]*
> *- Like for me, for me I'll almost avoid it…because I'm afraid that… something's gonna happen, I don't know. It's not the same. It's like an anticipation where I'm like whey, I don't know about that (FG 1).*

Expectations are not switched off when a person enters the health care system and becomes a patient. Food and drink do not magically become merely other items on the medication list. The participants in this study recognized that food and drink were not as the patients under their care expected them to be:

- Sometimes the vegetables are overcooked. They complain about the broccoli.
- The broccoli comes in correct, it's just in the warmer until it's lunch time.
- And the meat sometimes doesn't taste like you think it should taste. Because it would- like the meatballs, they put too much bread or something.
- The food comes in, if it's already done, it still, I guess well, here, it probably has to stay a certain temperature, but then that means it's constantly cooking. But if they turn it down, it'll stay warm.
- Yeah, but that won't help the meatballs [laughter] (FG 4).

As often as the food was the focal point of a conversation was the act of feeding. When people were talking about a favorite dish or an event they would talk from the perspective of the feeder. The vegetable pizza as discussed above was really about a certain way of making the pizza as expressed by the person who considered it her dish. People also saw the act of food preparation as a way of bonding with family including helping children with schoolwork:

Also at home, you helped prepare food together, you're talking about your day. And as- then, you're drawing your children to help you prepare the food. They're more apt to talk to you about what happened that day. And then, it has a tendency to be healing, in the sense that now it nourishes your body. It makes you feel good (FG 4).

- It can also be used as a teaching tool.
- Yeah, math [agreement].
- It's about fractions (FG 4).

People clearly felt that that the act of feeding was more than just mechanical preparation of a substance: the role of the feeder connects you to a loved one. Health care providers make recommendations regarding changing or limiting what food types a patient may have. But family members visit and bring food that they have prepared (which does not align with the recommendations) in order to maintain a relationship, to give care, to show love:

- I think it gets into the ethics of life, in my facility, in the nursing home, you know I have lots of little ladies that tell me "I love him and I feed him this because I love him"… you know and it's kinda like, "well, you're killing him" but… but…
- Yeah

- But where does this end?
- Right. Those are end of life issues. What do you say when someone's end stage dementia? And she has spent her whole life caring for him whether it was feeding him, dressing him, whatever. And she looks you dead in the eye and she says, "I love him, that's why… I know he likes this." …… And no amount of education is gonna change that.
- I would echo that. Lots of different emotions connected to fact but absolutely expressing love and concern care and it is comfort. But it's also an expression whether it's the preparation or, "That I fixed your specifically favorite food," or whatever (FG 1).

4.4 "NUTRITION/HYDRATION" VERSUS "FOOD/DRINK"

When asked what the words "*nutrition and hydration*" meant to them, one person went straight to feelings of anxiety This was an SLP whose job is to assess and manage swallowing disorders, a person who knows that bodies need food to survive, and that word nutrition is technically about food. And yet the reaction was clearly different from the discussions of food:

Anxiety. Many people's anxiety, can be ours, can be the patient, could be the family, can be [crosstalk] everybody really who's involved can be anxiety. You can [inaudible]. Different kinds of anxiety, Different sorts of anxiety. For the family, the anxiety at this level, and perhaps not making it through whatever has happened. The patient's anxiety of what's going to happen and what are they going to do to me [chuckles]? Our anxiety about, "How will I be judged depending on how I handle this case"? (FG 2).

Some participants reflected on the nature of the meal and some on the setting. One group closely considered the words and when they would use one term or the other, or could they simply be interchanged. The discussion then delved into how which word one used changed the way that they thought about the person and how the words dehumanized the patient:

- Because I don't know if it's okay either way. I can say, "I'm going to provide to this patient nutrition and hydration, or I'm going to provide to this resident or patient food and drink." But when I might say to you, "Let's go out for some food

and drink", which I wouldn't really say, but I could say that, but I'm not going to say to you, "Let's go out for some nutrition and hydration."
- You're not going [to say] to your parent some nu- some nutrition, and hydration. Give a parent some food, and something to drink.
- I think nutrition and hydration sound more like, severe, like,
- Sounds like, not, you're not talking about a family person anymore.
- It's not fun, no.
- Before we were talking about a family person.
- Like a patient.
- And that's what it is [whispered]. Oh, that feels crummy.
- Yeah, that does feel crummy. [someone whispered "WOW" and group looked down and shook heads]
…[PL asked] So, why can you switch it up? You can use the four terms interchangeably with a patient, and yet, you're showing some discomfort at the fact that you can't do it with non-patients. And the discomfort seems to be about why do you treat that differently?
- Yeah. This is kind of a yucky discovery. It feels like, I wanted to say something like, it feels like an empathy or a compassion issue, but I think it's a humanization issue (FG2).

4.5 REASONS FOR PRACTICE PATTERNS

The health care providers reflected on their practice and what pressures led them to act in certain ways. SLPs and FLPs do not engage in practice with immediate and high risk such as say, surgery. Despite this the first response was one of fear of mortal outcomes, blame, and litigation:

I don't wanna kill them. That's my biggest concern. I don't want to cause them death. Or assist with that… because I don't wanna be blamed (FG 1).

I think people are also aware of being you know sued as a possibility. I think that… (FG 2).

I'd say, for one, for the consistency I guess, because they're scared. And they also want to make sure that they're doing the right thing so they don't get in trouble. I guess, recommending it for somebody if they don't want to put them on a certain diet consistency that they can't tolerate (FG 3).

Tied in with the fear of litigation is a concern over how health care providers are supposed to behave, how they are trained and what the larger community expects as received wisdom:

> *- It's what we're taught to.*
> *- It's what we're told to do. What we're ethically binded to, it's part of our profession.*
> *- It's accepted.*
> *- It's expected (FG 1).*

People also reported that their practice had changed over time and with context. A common comment was that experience allowed health care providers to see the world from the patient's perspective and that influenced their recommendations:

> *So, so when the family says, says, "well, I'm sorry but he can only have this," well, give it to me, let's go, because if that's all he's gonna drink and the only taste that he likes, well, I might as well start doing therapy with it. You know but I think, I think when people think of it as "I'm in the hospital, I don't wanna be here, I'm mad, I've no control, I've had this horrible stroke, and you're gonna give me this kind of food, are you kidding? You expect me to get better? [Emphasizing by striking table]" And you know we hardly have anything to say because this is just what we do. You know, until we're the patient we don't truly understand it, and you know, when I'm kinda looking at someone and "You're right." And we kind of go back to the "what can I do for you," because I'm realizing what I'm doing isn't helping (FG 1).*

With time and experience comes the realization that unlike what has been taught in school the world does not follow standard disease or recovery paths. And to better serve patients health care providers must develop a degree of flexibility and understanding of blurred lines, or even no lines, and feeling pulled in two different directions:

> *And some of it is how we've been trained. I mean, I know, you know, how we've been trained and some of it is you have to kind of de-condition yourself to the way you've been trained, because it's very regimented on how you do things. you know, this is it. The speech therapist's recommendations were this, this is what you do. There's no black and white. I mean it's black and white, there's no gray.*

And, and, you know, as time passes, there's a whole lot of gray, a whole lot of gray. So [chuckles] (FG 3).

4.6 PROFESSIONAL COLLABORATION

Participants recognized their role in providing on the job education given the importance of collaboration with health care providers from different disciplines. Again the grayness of the subject is a challenge along with the structure of a system that does not reimburse for education of other professionals, and equally worryingly patients and families. Nevertheless participants shared examples of collaboration and some ways that they tried to optimize care, or at least minimize disruption:

- Maybe talking another time to… say the direct care staff they don't have the same level of education as the nurse or the doctor or the professional staff member, but they're there all the time, and many of them really have a deep connection with this person, they want them to do well. And if you take the time to explain, "well, this will make them safer, it takes you more time and you may have to ask for some backup so that you can cover everything you need to cover, but it will make them safer so it's worth it."
- The aides are so, so critical, yeah, [group agreement "yeah"] they know those patients better than anyone, they're the ones that are feeding them [group agreement] when you're not there so they need a lot of training.
- Yeah, yeah, and reaching out to those people on different shifts, I mean, we're basically day-turn people by trade, you know, so the people who are on afternoons and midnight, they're still passing pills, they're giving meds, they're doing snacks, making sure that you touch base with everybody, not just the people that you see, you know, every day (FG 1).

Both the SLPs and the FLPs recognized the importance of the staff who see patients daily, perhaps hourly, and that their observations and input are crucial for patient care. In situations where a patient may choose not to follow the professional recommendations, the team must be aware of all the information and be of a common understanding:

- Bring it to your health care worker and your IDT [interdisciplinary team]. Are you aware, I know this is what you all think but I work with this person, this is what I see and…
- You have to make sure everybody's on the same page [crosstalk]. [agreement]. You have to make sure everyone knows that this person, this is the path of their choosing, and we're all aware of it, and we can support her in that. It is what it is. That's her choice (FG 3).

Decisions around eating and drinking get more difficult as the clinical situation gets worse. When a patient makes decisions but the family do not understand the chosen course of action there can be much upset. The participants were deeply troubled when the professional they felt should be having "the conversation" was either not doing so, or was not including all parties. Participants expressed frustration when they saw issues not being addressed and families distressed:

- Does any other professional know that this is happening? And is anyone gonna step up with me?
- Right. Are they gonna back me up?
- Um, pulmonology's constantly contradicting what... things have been done because they don't know… they didn't look at all the testing or… the doctor says, "well, I've known this person for so many years, and this is what they want." And I said "that's fine… but I think you need to discuss some of these things with the other family members who don't agree, because the patient's not really getting the service… whether that is [emphasis] letting them have what they want right now, and that is, that's fine, the patient can understand but the family can't." Or that the doctor and the patient always had the relationship together, the patient was always in the room by themselves with the doctor, and the family was never privy to [emphasis] any other information, any discussions of DNRs and what would you wanna do if you couldn't swallow, or what would you wanna do if, if we thought a temporary tube would benefit you… how do you know it would… and maybe, maybe it's how I [emphasis] feel, you know, I don't want it, I don't want it, I don't want a tube. Either I'm gonna do it or I'm not, I'm gonna make it or I'm not, and I don't want it, and but you still have to help them understand the options [group nods, "right"], and it's really, really hard to set my personal bias at the door, and not [emphasis] help them understand that it would require a level of surgery, it would, it would potentially cause pain. Some of the things that I end up having to say that I really wish the doctors would have said sooner, or… or even just in general conversation with a family who is going through... "So he might get better..." I always hear this: "we can't say how long, we can't say what's gonna happen, we can't say, we can't say…" Well we can say what's

happens if you're malnourished and dehydrated. I think at least that level but they don't ever want to go there.
- "They" being? [PL asks]
- The doctors (FG 1).

The final point in the previous quote relates to the difficulty with prognostication in health and disease; that it is often impossible to predict many outcomes with certainty. But what this participant felt should be addressed was the real danger to people who are not receiving nourishment or hydration: serious complications and even death, and yet the physician would not "go there".

Not all conflict is at a team level. Sometimes it was how an individual was interacting with a patient and this could be any health care provider. This failure at a basic human level is equally distressing to the observers:

- And again, best intentions and then there are the times that it feels like to my observation, which could be totally wrong, there were really no good intentions and the person was wearing the food. And they're talking- and the staff was talking about how horrible the food looks, and "I wouldn't eat that. What is it"? So it's horrible [crosstalk].
- "It looks like dog food, why aren't they eating?" Yeah.
- And, and it just makes me want to cry. And sometimes I say something and I maybe don't say it very well. But, I just want to say, "Hey," sometimes I do, "They're eating. Stop" (FG 2).

4.7 PATIENT CONTROL

The major issue raised by participants to do with the patient experience was that of *control* or rather lack of it.

- I mean, it's a world of difference, it's, it's and why should [emphasis] it be pleasant in the hospital, to eat? Because we're not putting them at a table, with a vase and a flower, nothing is pleasant or pretty about dining in your bed with a

tray covered with used Kleenexes, and stuff you've pulled out of your throat and… everything else sitting right there… next to you.
- Or the urinal.
- Yeah!
- Or it's 4.30 in the afternoon or 7.30 at night and you're either not hungry, or overly, or so overly hungry that you're nauseated [group mm hmms]… so.
- Or it's cold ["mm hmm, it's cold" agreement].
- Or it's cold.
- When it's not meant to be cold, cold things are normally hot, and hot things are cold.
- So it's not home, it's not home [group mm hmms] (FG 1).

Participants found ways of increasing patient control that also helped their health care provider role. Participants shared their reactions when a patient says "no":

- Because you think one, I even think in my mind this is what I'm going to say 'cause I have to say it, and then I wait for the patient to say, "Well, I'm not going to do that." And in a way sometimes I'm relieved, and I'll just document what they said, and then I will respect their wishes, help make it as safe as possible.
- I'm happy when people eat and drink what they want. It's fine with me.
- It's kind of a relief and where's the anxiety at that point because they've made the choice, and you're going to help them as much as you can (FG 2).

4.8 ECONOMIC CONCERNS

Both the SLP and FLP groups raised concerns with economics impacting clinical practice. Certain tests are required for the SLP to assess the swallow and recommend strategies but only physicians can order them; the problem is that they do not do so. Participants shared how they try to work around the situation when their patient is going from the community care facility to the acute care facility and will be temporarily under the care of a different team:

- Or you have a doctor at the nursing home that you know will not… sign up for something that's very critically… that needs to be done. How far up do you go? [group "right"] Do you disagree with the doctor or do you just… go to the family and talk to the family about it, or… you know… um, it's a game, it's a game.
- "You might want to talk to doctor so and so about blank."

- Well, "when you take your family member back to the er, hospital why don't you have a speech consult done?"… and then I'm on the phone to the hospital [emphasis] so they know "so and so's coming would you please [emphasis] do this before they send him back?" Is that ethical? I don't know… but [inaudible].
- It's giving them a heads up"
- No doctors' names get mentioned, nothing gets you know… it's just "we need a speech consult for this person," because I feel helpless, when I see the clinical signs of things that I get turned down for "unnecessary expense", or it's their payer source (FG 1).

Fewer staff are required to care for people on feeding tubes than to supervise meals or hand feed people. FLPs expressed concern over whether they were qualified to deal with feeding tubes in other places that they had worked and felt it was to do with cost cutting:

- And you know what? You have a good point about that. Because where I worked, he had a feeding tube. None of us were certified to deal with that feeding tube. He had me dealing with the feeding tube. And I thought it was unsafe for him to be there among other participants that were mental health and mental retardation. But it was all about money.
- Or about less care?...
- Yeah, you don't really have to deal with them as much. As far as the facility craziness, you set that machine and you walk away.
- You're done mmm hmm.
- It's less care.
- [PL offers water and encourages group to continue]

- The facility can save on staff if they're on tubes. It's more or less you just need a nurse and maybe an aide instead of having, if you're on one unit, you just need three or four aides since they're on machines, the nurse will hook that up, you've got an aide to change them, bells go off, and you're saving money (FG 4).

4.9 IMPROVING THINGS

During each group, even before the final question that targeted how to make things better, participants raised points about how they were working to improve the situation with patients, families, coworkers, and their own feelings about their work. This section will address how the

lot of the patient and family might be improved. Along with control the other c-word to frequent discussions was compromise:

> *- Uh, compromise.*
> *- Compromise?*
> *- You know, they might, uh, we recommended that, uh, that we can't alter diet and thicken liquids and we can, you know, have a meeting and say maybe, like, "What's the most important? What's the, out of the two, what's the worst?" Maybe it's the thickened liquids, but they, they do a little bit better with regular through trial and error, like you know, trial 'em and see how they do, they might be okay, um,*
> *- Certain things.*
> *- On certain things (FG 3).*

Inherent in compromise was the understanding that education was required. Enabling autonomy does not mean letting the naïve patient pick anything they like. Participants discussed the fine balance of listening to the patient, finding out what they do not know, what they would like to know, and what you professionally think is a good idea. Despite recognition that education is crucial to decision making it is not generally a reimbursable component of care and yet health care providers try to sneak it in:

> *- Taking that extra initiative I guess to continue, to continue when it's not making sense is… really, maybe you need to get back in there, I mean even though it's not billable even necessarily is to just take that extra step just one more time or two more sessions or repeating myself just again,*
> *- And listening though.*
> *- Yeah, and listening, and waiting for that response.*
> *- Asking how can we make it better for them.*
> *- Right and listening, just listening to them, "here I give you all this information, what do you think about it or what are your questions, what do you love or hate about it? Maybe giving them all this information but at the end of the day when you go home what are you actually gonna do [group agreement mm hmms]? Because if you're gonna do none of this then, let's talk about that. You know. If you're gonna go home and drink your Pepsi, and have your PB and Js.*
> *- You gotta cut them so you can eat 'em.*
> *- Yeah (FG 1).*

This last part is vital; to know what people do when health care providers leave the lunch room or patients go home. Several groups echoed the importance of building relationships with patients so that they feel safe enough to be honest and the health care provider flexible enough to compromise over what the patient admits to.

Compared to drug regimes, infection rates, or high risk monitoring, some aspects of the eating and drinking treatment, as such, profoundly impact the activity. Participants felt addressing factors that affect the experience are crucial to the outcomes of care. What was important to the participants as feeders and feedees in their own world, was equally important in their health care provider world:

> *- But it should be pretty, it should be pretty because that's what stimulates eating.*
> *- Yes.*
> *- 'Cause that's what you're used to on the exterior.*
> *- And if you've got a roommate in your room and there are bathroom smells, if you can smell, if [emphasis] you can still smell, if you can still taste, you've got those things or you've got conversations going in the hallway that aren't pleasant to listen to [group mm hmms], if you're cognitive enough, to have awareness, so (FG 1).*

> *I think along the lines of how we present ourselves like being more gentle with them and making sure the slop's not all over their face. I mean, because it's just, and how the food looks that there is a reasonable facsimile of what it really is instead of a blob of food on their plate and in the nursing homes because one of the places I go, it's really nice, that they do the other two and one is really horrible that it just all runs together. And I've just always like, I don't even, I feel terrible giving them the thing. You can't even tell what it is by smell which is really bad (FG 2).*

> *- So now they will put the food on the plate, and pass it around in the main day center, I don't think you guys do that?*
> *- No.*
> *- They'll actually ask, so that the participants can see it, maybe smell it a little bit, get a picture of what they're going to be eating. So then they can say-- tell the aide who will then go to the kitchen and say either no, "Yeah, I want that," or "No, I want something else" (FG 4).*

Participants clearly thought of food and feeding as less medical treatment and more like a human interaction that they probably experience every day outside of work. Current reimbursement models do not support that sitting with a patient and taking time to help him eat, is a medical treatment. Such an approach to care would positively impact patient outcomes:

> *Yeah, and on the same side as that, if like a participant in our facility, or like in nursing homes or something, if they need fed, it's important to me that somebody takes the time to sit there. 'Cause oftentimes, like in a nursing facility if they're low or understaffed, they don't have the time to sit there and make that one-on-one interaction that would probably make somebody eat more than left to themselves (FG 3).*

5.0 DISCUSSION

This is the first study that we know of to explore health care providers' views of nutrition and hydration in the clinical setting versus eating and drinking as a human experience. The health care providers responsible for the assessment and issuing of recommendations regarding the provision of nutrition/hydration (SLPs) expressed identical thoughts to those responsible for the day-to-day work with patients and families (FLPs). Nutrition and hydration are synonymous with medical activities such as the provision of medication: how much, how often, what form. Nutrition and hydration are considered essential for health and survival and under the control of the health care facility. Reflection on the human experience of eating food and drinking liquids shares such perceived benefits as health and survival, and triggers a wealth of other feelings and attributes. Health care providers shared concern that they sometimes do or advise certain things due to a fear of litigation, due to historical training, or as a safeguard knowing how care might be provided once they leave the patient.

5.1 RESEARCH QUESTION 1

How do health care providers view the provision of nutrition/hydration in the clinical setting compared to how they view eating/drinking as a human experience?

Common across all groups was the idea that nutrition and hydration, eating and drinking were required for health and life. This is part of daily living and clearly it is required in health care no matter what disorder is being treated; people still need fuel for the biomechanical body. This is not a surprising finding; ask any group of people what they need for life and they will respond with food, air, water and perhaps shelter, companionship. Thus ask them what food and drink are for and they will circle to requirements for life.

Nutrition and hydration in the clinical setting are approached as with other medical interventions: monitored for how much, how often, composition, and output. A major difference between the clinical world and the human world is where the *locus of control* sits with food and drink. A health care provider is usually in charge of medications or tests. These are in and of the clinical world and as such patients and families are familiar with that construct. Food and drink are from birth-to-death activities of healthy humans and controlled usually by the individual unless too young or impaired to manage without help.

Eating and drinking are first and foremost a human activity, certainly of sustenance but more of identity and community. Across all cultures meals are usually taken with others and when restrictions are placed on what or when to eat, it tends to be for cultural reasons. The participants in this study shared that eating and drinking is a way of socializing, of celebrating life events, and of connecting with other people distant in time or location. There are expectations around how certain dishes will look and taste and when those expectations are not

fulfilled people are unhappy. Surely a pizza is still a pizza? Subtle differences in the preparation or in the taste of a dish significantly impact the way people experience food. Particular food items carry meaning and even embody a loved one who is not present. This is not in the religious sense such as the Roman Catholic sacrament of communion and consuming a deity, but in memory and love.

Eating and drinking have meaning for the consumer and for the person doing the preparation. There is a sense of pride, of love and even worry: will it be good enough, will it match expectations. For the preparer of a dish associated with a particular person there may be a tradition that such a food item will be produced at gatherings and enables people to feel a connection to the person. In this study *Aunt Mae's salad* was prepared by the daughter of someone who had died. Aunt Mae's salad was an expected dish at family gatherings and the daughter felt a responsibility and happiness in the associations this dish provided.

Participants reported spouses feeding their loved one because of devotion, a history of caring, it was a favorite dish, and perhaps, all they had left to connect with someone with advanced disease who was no longer able to communicate. "How do you counter that?" the health care providers asked. The act of preparing food and feeding is a part of how people view themselves, their role with loved ones, their connections with friends and family. Recommendations to minimize harm and do good regarding the consumption of food and drink impact much more than the swallow mechanism. Even in instances where the food was possibly causing more physical harm than good, participants reported unease restricting the feeder and recognized the ethical complexity of such situations.

Reflecting on the meaning of words such as nutrition and hydration, food and drink led to discussions of how they cannot simply be interchanged. Nutrition is not a synonym for food,

hydration is not the same as drink. One group delved into this idea in some detail and came to the realization that for them there was something deeply uncomfortable when they realized that use of the terms nutrition/hydration was associated with them no longer thinking of the patient as a person (see section 4.4).

Participants discussed the importance of the setting and how food and drink were provided in health care facilities. Eating and drinking are impacted by the physical setting: trays covered with used Kleenexes, eating with smells from bathrooms, other people talking of unpleasant topics within earshot of the eater, disengagement and isolation. Even with one-to-one feeding assistance the eater may experience food smeared across the face or dripped onto the body, rushed feeding, the feeder commenting on the unappealingness of the food, or even ignoring patients and talking over them to others.

5.2 RESEARCH QUESTION 2

What factors do health care providers identify as reasons for the discrepancy between clinical knowledge of an intervention compared to recommendations regarding that intervention in certain cases?

Previous research showed that health care providers recommended or performed certain interventions even in the light of evidence showing that the interventions did not produce the hoped for outcomes (Sharp & Shega, 2009). Health care providers have also been shown not to comply with professional recommendations for a variety of reasons (Chadwick et al., 2002; Crawford et al., 2007; Pelletier, 2005). The data in this study revealed that both SLPs and FLPs

followed the same paths when confronted with recommendations (accepted professional practice or specific patient recommendations) and those paths could be agreement or disagreement. Figure 2 represents one possible model of the options based on the discussions for this study. Of most interest is when a health care provider chose to go against the accepted course of action.

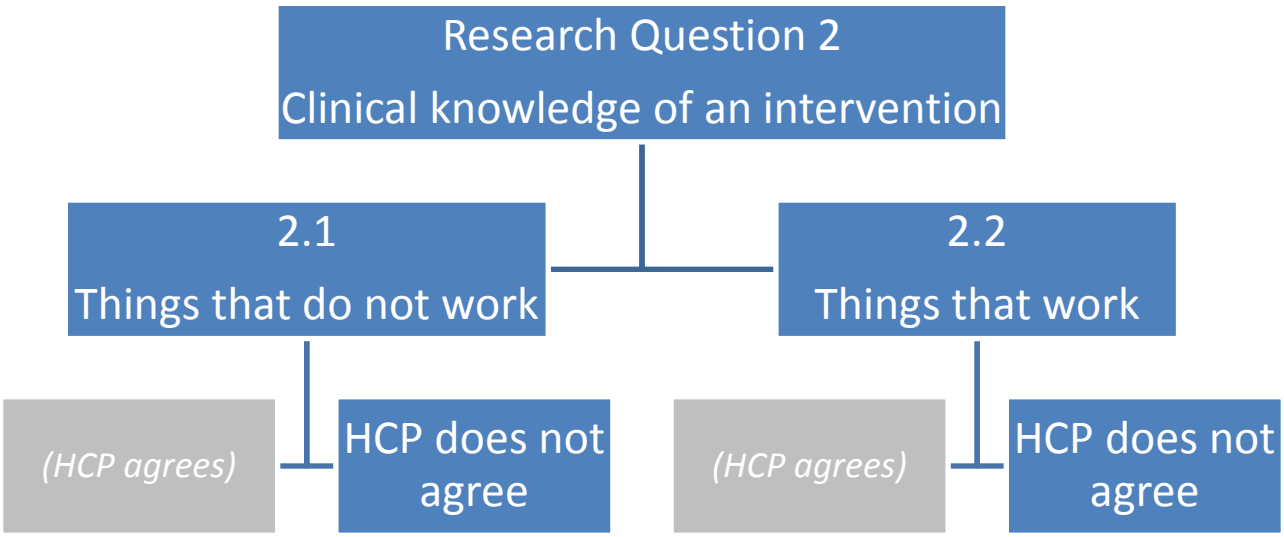

Figure 2: Research question 2 response directions

5.2.1 Interventions with little or contrary evidence supporting use

The first reasons raised by participants for supporting an intervention without good evidence backing were fear of doing harm to a patient and legal repercussions. The clinical world developed a fear of swallow complications based on little evidence and with regard only to the biomechanical model: it is slow work to undo entrenched professional anxieties. In a highly litigious society like the United States fear of a malpractice suit is often a primary motivator for

defensive medicine (Studdert et al., 2005). The difficulty with swallowing problems is that negative outcomes do not appear immediately as with say, choking, when the airway is blocked. Even aspiration pneumonitis, which is a rapid onset reaction to gastric material being refluxed up the esophagus and then aspirated into the lungs (thus not a swallowing problem), takes hours to days to become evident (Marik, 2001). Chest infections come from pathogens entering the lungs which is much more likely from dirty oral secretions which pass into the lungs constantly. So the theory of reducing the risk of a chest infection by altering or stopping oral intake is not based on clear evidence.

Another critique of the approach to care with eating and drinking problems is the presumption that diet modifications are a benign intervention. People do not like thickened liquids and the most vulnerable patients, those who lack the communicative ability to state their wishes, often can express their dislike only by turning away or other combative behaviors (Wang, Charlton, & Kohlwes, 2016). Such behaviors may result in chemical or physical restraint, for merely expressing dislike of an abnormal substance. In fact, Wang et al. (2016) bluntly state that "perhaps one reason that thickened liquids are viewed as benign is that they are described with the adjectives "nectar" and "honey" thereby implying that they might be pleasant to drink. This wording is at best euphemistic" (p. 735).

Health care providers trying to follow models of best practice often struggle to find the evidence to support their work. The research base supporting clinical hypotheses and interventions is gradually developing but it is small and contradictory at present. The nature of eating/drinking/swallowing/feeding impairment is subtle and multifaceted. Thus a defensive approach is more likely given the effects of a dramatic headline such as "patient chokes on sandwich" when most people do not understand the difference between choking and dysphagia

or aspiration. Everyone is at risk of choking, and everyone aspirates, the question is not whether you aspirate but what you aspirate, and then what other strengths and weaknesses your system has to cope with an insult.

5.2.2 Interventions with evidence to support their use

The second main rationale behind altering practice may be viewed as one of defiance. What the participants in this study shared was that over time and with increasing experience many people changed their own practice. Such adjustments were rarely a result of dramatic changes in the evidence base or in best practice guidelines (often eminence based practice, i.e. expert opinion) and probably required a degree of courage to challenge the status quo. A model for addressing culture, preferences and ethics in dysphagia management identified four key themes required to support shared decision making: communication, reflection, imagination and courage (Kenny, 2015). Advocacy for one's patients is commonly taught but courage in this model required that a person stand up for the individual patient, perhaps to the clinical team and/or to the received wisdom of the culture within which she is operating.

The nature of this change in practice was much more about compromise and consideration of the bigger picture(s). Participants talked of working with patients and families to find some middle ground when possible: being less restrictive with one item or starting work with a favorite food. In some situations it was reported that love and care giving took precedence over likelihood of a poor medical outcome. The judgment of a poor outcome is very individual. A recent small study (n=180) of hospitalized patients with serious diseases showed that over 50% of participants rated needing a feeding tube to live or being dependent on others for continual care as states equal to or worse than death (Rubin, Buehler, & Halpern, 2016). This

work has not been replicated with people on modified diets but a lifetime recommendation to never have normal drinks or for all food to be smooth and soft is likely to affect the experience of eating, drinking and feeding.

One might argue that such individual approaches to intervention are truly in the spirit of evidence based practice. In 1996 David Sackett and colleagues published a paper in the *British Medical Journal* attempting to clarify what is evidence based practice and what is not (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). The three cornerstones of such practice are evidence, clinician expertise and patient preference as it is often abbreviated. Sackett et al. (1996) attempted to clarify what these things mean. The sections below are one continuous quote but have been separated to show their evidence based practice "cornerstones":

- evidence

> *Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.*

- clinician expertise

> *The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice.*

- and the most misinterpreted of all, patient preference:

> *Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care (p. 71).*

What this suggests is that true experts look carefully at the person in front of them and consider the world from that person's perspective. Then such an expert brings to the table evidence and clinical wisdom and supports the patient or family in making the decisions that face them. There is no mention of defensive practice, following the locally received wisdom, or simply agreeing to whatever a patient/family wants.

5.3 CROSS-DISCIPLINARY CONCERNS

A common concern across all groups was when a patient was being fed or food was being discussed without due respect for the patient. Examples were given of staff talking in front of the patient about how the meal looked like "*dog food*" or that the patient "*was wearing the food.*" Such practice is unacceptable; and eliminating it could provide an immediate and cost free way to improve care although such disrespectful attitudes are not unique to care with eating and drinking. Staff said that it was important that they knew what the food was so that they could tell the patient and often they (the staff) could not tell what the dinner was supposed to be.

SLPs expressed concern that other health care providers did not realize the foundational status that appropriate nutrition and hydration have in terms of any area of rehabilitation. The SLPs offered that they would try hard to figure out who the key person was in terms of a patient's care, or repeat trainings to a variety of staff members to get the point across. The SLPs acknowledged that they were there only for a short period in certain shifts so messages were not always transferred. Relationship building with all those involved in the health care of a patient in a given facility was important.

Dysphagia is a highly individual condition due to many different diseases thus it is always a concern for a range of disciplines. An often reported tension in clinical care is when the health care provider tasked with managing a condition requires another professional to order required tests. In this study SLP's reported being professionally bound to base treatment on the results of a test that they could not order. The refusal of physicians to order the test may be for sound clinical reasons but there are also reports of refusal for economic reasons. The SLP is then caught between two unacceptable courses of action: do not treat the patient or treat the patient without the required information. Sound clinical reasoning needs to be discussed so the whole team is on board and gives a congruent message to the patient., SLPs need to be clear in the arguments for a test in terms of long term outcomes which may include economic reasoning. These two approaches may not resolve all of the conflict where for historical, professional or other reasons, one professional is dependent on another to practice.

5.4 EXPECTATIONS

Food and drink, eating and preparing meals are an individual identity marker, a trans-community activity, a lifelong experience. Expectations about all aspects of this activity develop at a young age, and get reinforced daily, impact lifelong relationships particularly as someone is nearing death. When a person develops a swallowing problem or other condition affecting this essentially human activity, the clinical world treats it like any other medical intervention.

The mechanics of eating and drinking may be altered physically with the aim to reduce risk but crucially the expectations associated with the food, drink and experience are not addressed. Expectations are held by both the patient and the health care provider and those

deeply held feelings impact how care giving and receiving are experienced. Even the familiar advice to have three square meals a day is professional advice based on evidence so in a sense it is like modified diets but one can still have expectations met and meaning experienced. Unlike with the prescription of three squares, when the recommendation to modify the diet, no one attends to the expectations and meaning which are so inherently a part of human eating and drinking. As noted above, the description of something as “honey” implies a specific sensory set (Wang et al., 2016) and when one is presented with a mug of hot coffee that has been thickened to the consistency of wallpaper paste following clinical recommendations, expectations are not simply unmet, but radically upset.

5.5 CONSENT AND DECISIONS

This is not the place for a lengthy treatise on informed consent but this study does contribute to the concept and how health care providers help patients and families with decisions regarding food, drink and feeding. Common in most frameworks for informed decision making is that parties should understand what it is they are making a decision about. Almost 30 years ago Appelbaum and Grisso (1988) clearly outlined the legal standards for competence (a legal concept), which are the same for a health care provider making a judgment about a patient’s capacity for an individual decision at a specific moment in time. The four standards are as follows:

- To be able to communicate choices,
- *To understand relevant information,*

- *To appreciate the situation and its consequences*, and
- To manipulate information rationally (Appelbaum & Grisso, 1988).

Even before considering people with impaired cognition or communicative ability this set of standards is pertinent to health care in dysphagia. To understand relevant information requires understanding of words and phrases and what these mean in terms of the treatment. To appreciate a situation and its consequences requires a patient or family member to understand what the treatment means specifically for him or her and his or her future. If in the world of dysphagia care the providers have different understanding and appreciation of consequences from the patients and families, then they will struggle to support them in decision making. If parties are setting out naïve to the other's understanding then the communication breakdown goes both ways. Health care providers need to understand the influence of their human experience on the care they recommend or provide in dysphagia work.

Health care providers also need to enable their patients and families to ask about issues that they are not even conscious of but which may have serious consequences on care, relationships and quality of life. Thus the burden on health care providers of living in two worlds may be used to their patients' advantage if deliberate and judicious use is made of their human-experience knowledge to inform their role in dysphagia care. All groups identified when they used their human experience to support their care work. This is an important contribution to what is acknowledged to be a complex decision making area where decision making algorithms and models are rare (Clarke, Galbraith, Woodward, Holland, & Barclay, 2015; Kaizer, Spiridigliozzi, & Hunt, 2012). Such algorithms may never be appropriate because they tend to be based on objective data and procedures for groups of patients. Decision making in this area is highly individualized and requires a teleological approach: understanding the specific human goals that

a patient and their health care provider are aiming for. As the National Institutes of Health state: "scientists seek to understand phenomena in the world—they want to describe what is—while bioethicists seek to figure out what people should do" (National Institutes of Health, 2009, p3). Much of the clinical approach has been driven by a scientific approach that fails to recognize that feeding goals are preference sensitive for particular patients and particular contexts. Thus the wise prescriptions of feeding plans require complex, shared decision-making that exemplifies high standards for patient involvement typifying the best intentions of contemporary bioethics..

5.6 A FINAL CHALLENGE

One group raised the issue of patients who one may perceive to have given up:

> *- Well you're… you haven't even talked about the biggest part is the denial… or the people who just don't care anymore. You know, how do you make someone care enough to want to eat? You have someone that has ALS and they refuse to admit that they're not gonna be able to eat in a couple of months.*
> *- Mm hmm… that's the grief [group agreement].*
> *- Yes (FG 1).*

When a patient decides that the goal no longer requires aggressive or even active approaches it is very challenging for health care providers, family and friends. What cannot be gleaned from the above quote is what was going through the mind of the patient: their understanding of the options available to them, the costs, benefits and potential harms of all courses of action. Generally health care providers try to establish the patient's level of understanding. The situation of a patient knowing that they have an incurable condition and how they react to that is complex and beyond the remit of this paper. Nevertheless the distress that the participants felt when this comment was shared was very real no matter what the patient perception.

What this concern does highlight is that the SLPs may feel ill equipped or perhaps not even licensed to engage with patients' grief when they learn about how their eating and drinking cannot continue "normally". Indeed, the profession is founded on diagnosing and managing conditions which for the most part are concerned with loss: loss of the child without a future in autism, loss of communicative or cognitive skills following a neurological insult, loss of one's future with a spouse due to the diagnosis of a degenerative condition, and loss of the human experience of eating and feeding. Nowhere in the Scope of Practice, or Preferred Practice Patterns for the Profession of Speech-language Pathology is the word grief to be found (American Speech-Language-Hearing Association, 2004, 2007). Skills in supporting patients and families to cope with loss should be a fundamental part of clinical training yet it is not. The vast majority (80%) of SLPs surveyed in their first year of practice did not have counseling credit hours in their educational programs (Phillips & Mendel, 2008) and the top area that such novice clinicians reported they needed more training and support in was parent counseling regarding children with impairments (Rowenhorst & Stuart, 2011).

5.7 RECOMMENDATIONS FOR FUTURE EXPLORATION

The SLPs had a range of experiences but they all worked in longer term facilities. Thus they (and the FLPs) could build up relationships over time with patients and families. One avenue for comparative research would be to explore the experiences of SLPs who work with different populations e.g. in the acute care setting. Acute care providers rarely work with patients or families for long periods so do not build up relationships or see the devastating effects that their well-meaning restrictions have on lives. Acute care focus is of a much more immediate nature

and perhaps some of the pressures the community based health care providers reported are felt more keenly such as fear of being the lone voice to challenge the status quo.

If duration of practice helps people to be more reflective, perhaps it might be developed earlier in a career or even in clinical training. How do novice health care providers think about this topic and how does that impact the recommendations and discussions that they have with patients and families?

6.0 CONCLUSION

Food, drink and the act of feeding are central to the human experience as an individual and as a member of a community: a lifelong act in sickness and in health. When a person's swallow becomes impaired the human act is transformed into a clinical process. As the world's population increases more people will experience conditions that impact the swallow mechanism. Medical advances have compounded this situation with fragile people of all ages now being offered intervention and hope. Intervention is often fraught with contention and contrasting opinions, and decision making is difficult for everyone. The legal system in some countries has decreed that the provision of food and drink under certain circumstances is a medical treatment and thus can be withheld or withdrawn as with any other. The distress experienced by those involved in decisions in this area is widespread and perhaps felt more keenly than with other areas of health care.

6.1 SUMMARY

This study directly contrasts food, drink and the human experience of feeding another person, with the medical interventions of providing nutrition and hydration, and asked those who experience the dichotomy most keenly to share their thoughts and concerns. The causes of impaired swallowing and possible approaches to intervention were outlined, research questions

developed and then empirical research was undertaken using focus groups comprised of SLPs (those who diagnose and treat patients with swallowing disorders) and FLPs (those responsible on a day-to-day basis for implementing recommendations and restrictions with food, drink and feeding). The data contributed by participants were discussed in relation to prevalent themes, concerns, and solutions to decrease the distress felt by all stakeholders in these complex decisions.

6.2 LIMITATIONS

A major limitation with any study method requiring volunteers (survey, interview, focus group etc.) is that people self select to participate. Thus you may have extremes of view; as with restaurant reviews, it is only those with very positive or very negative views who are fired up enough to spare the time and energy. The SLPs were relatively experienced, motivated enough to be attending a professional conference often at their own expense, and possibly of a subset who were interested in exploration and change of practice. This is preliminary work that aimed to uncover how people think about a topic rather than a definitive guide to the world view. Even in this small data pool there were differences of opinion.

The researcher [PL] is an internationally recognized speaker on the topic of decision making, and challenges current restrictive practices and risk averse, unsupported approaches to intervention. It is possible that the participants chose to attend because they were aligned with the researcher's viewpoint, and as the researcher defined the themes of the discussion, the results are a self-fulfilling prophecy of sorts. It would be a strong character, or a very disgruntled one, to attend a group with a conflicting viewpoint. The benefit of the researcher's reputation in

attracting participants is also a weakness in terms of possible bias. For any focus group no matter who the facilitator is, the concept of social desirability must be borne in mind. People give you what they think you want to hear: students, patients, and focus group participants, thus effort should be made to encourage all and opposite contributions.

For preliminary work such as gathering ideas on a topic it is important to keep in mind that even the language used for questions presumes some perspective and thus biases the data that are received. To constrain participants to addressing the topic under consideration will always result in this bias.

Research that aims to uncover people's thoughts on a topic can never be all encompassing, and any such claims should be viewed with a degree of caution. The quotes chosen to highlight themes are only a sample of the transcripts and these transcripts are rarely published in full (though as with any research data they are available to all who request them for a period of years). The intention is to show trends, associations and contradictions where they appear.

6.3 THE METHOD ACTIVATES THE SOLUTION

The act of discussing the concepts of interest may have started a movement to improve the situation of the patients and fellow workers that the members of the focus groups interact with. Participating in a focus group allows people to air their personal thoughts, to hear alternative opinions and to have their perspectives confirmed and/or challenged; this has been referred to as "clients convening" in market research (Langer, 2007, p. 33). Clearly the researchers gain an understanding of the thoughts on an issue. Equally important may be this convening starting the

process of dialogue and development of better practice in the clinical settings. Thus by participating in the discussion about the problem, the group starts to address it. The groups had already identified issues and started to address them before this research study began and further ideas were generated in the discussions.

6.4 BIOETHICAL SIGNIFICANCE

Over the last century there has been a significant increase in the number of people with eating/drinking/swallow problems associated with medical conditions that can now be treated to some degree. The medical and legal worlds have, at least in many western medicine cultures, separated out the treatment of providing nourishment and hydration from the common acts of eating, drinking and feeding. This may help in some situations but to those involved it is clear that altering, restricting or even replacing meals with a bag of nutrients and a tube is really no replacement for the feeding activity at all. The aspects of feeding that lie below the iceberg's waterline may contribute to the emotional upset and contention evident in almost every clinical case where health care providers alter how someone gives or receives food. Modifying the act of feeding affects all parties involved: the person receiving the food and the person offering the food.

Understanding how health care providers think and act regarding nutrition versus feeding is crucial to addressing the conflict in relation to the care of their patients with swallowing difficulties. Health care providers are tasked with helping patients and families make decisions about clinical goals and care. Food and feeding is unlike any other clinical intervention because patients and health care providers have a lifetime of experience and expectations about how the

human activity should happen and what it means to them outside of the clinical setting. There are some similar interventions such as consideration of an ostomy for waste removal where humans have shared experience and expectations. Defecation is not generally an activity that signals identity or membership of a community, nor is there much choice in how/where/when to signal personal preferences.

Food, drink and feeding are perhaps the most stable of human experiences for an individual derailed by disease and illness. Disease and associated care can alter many aspects of a person's life but the disruption may not be felt as keenly as with food culture because other facets of life particularly in western, consumerist societies, are more transient than they were historically. Once a person is deemed to need medical care, this part of their life (or that of their loved one) must bend to the needs of the institution whose requirements are radically different to the human experience of eating, drinking and feeding.

Clinicians aim to do good (be beneficent) and what may need to be addressed earlier in education is what "good" means. For much of the lifetime of the SLP profession, the model in swallowing impairment focused on avoiding a narrow range of physical events which may or may not have negative sequelae. Recent work is starting to show that the physiological picture is more complicated than SLPs were taught, thus the risk analysis is not as black and white as presumed. Thinking from a philosophical perspective this idea of doing good and helping people to flourish is much broader. The telos, or purpose, of eating and feeding is much more than the techne, the doing, of medically framed nutrition. Understanding that the range of human goods involving food and drink is much more expansive than biological fuel would help health care providers to challenge the medically based nourishment-imperative. At the same the duty to be

beneficent would be supported because the health care providers would be doing good and preventing harm.

For many patients the decision is which option to choose from a number of poor alternatives rather than a clear best outcome that fixes things. This situation requires a higher level of thought regarding what might support the patient to flourish even if that flourishing does not slow the physical disease and bodily decline. Such a focus also supports the ideal of autonomous decision making. This should not just be allowing a patient or caregiver to do what they like or putting decisions solely in their hands, but to ensure that they understand the broad costs and benefits.

Clinicians are knowledgeable and have contributions to make based on their learning which is why patients consult them. Learning is more than studying in school or simple years of experience. To gain what Sackett et al (1996) were referring to as true expertise (see section 5.2.2) requires reflective practice and challenge/teaching from others more experienced. Such developed practice aligns with the Aristotelian concept of practical wisdom or phronesis. Daniel Hall, surgeon and Episcopalian priest, wrote of “The guild of surgeons” as a community of practice (Hall, 2011). Novice members of the community are guided in a type of apprenticeship as resident surgeons learning technical skills but also the process of how to decide, act, and advise patients in the many unique situations to come. Hall argues that this apprenticeship component must be defended in the drive to change and improve medical education or all that will be passed on is technical skill.

Reflecting on how SLPs are trained there is a stark lack of this formal guidance. They study for two years at the graduate level, spend 9-12 months in a clinical fellowship with minimal supervision and are then largely on their own (American Speech-Language-Hearing

Association, 2016). And yet many find themselves working in these ethically complex areas where knowledge and skill requires reflective experience not just book learning. This may be why the researcher [PL] is in such demand to provide continuing education on decision making, end of life, and the complexities of feeding. It is not an apprenticeship but perhaps indicates a need for something similar for SLPs to professionally flourish in certain fields of work.

Addressing the difficulty that health care providers experience and understanding the reasons can help reduce incongruences in dealing with eating and drinking issues. Perhaps if health care providers are encouraged to reflect on the duality of their worlds with eating and feeding impairment, and this is respected by other members of the clinical team, then their internal conflict can be reduced. SLPs should be encouraged to reflect carefully on how their recommendations affect the FLPs. Physicians should appreciate the factors they need to discuss with families before the SLP or other health care provider is involved. This requires improved communication between health care providers on concepts such as decisions regarding eating, drinking and feeding ideally before situations arise, as SLPs may be called to see a patient before the physician even sees a patient in some settings. Reducing the ambiguity surrounding an issue for health care providers contributes to reducing the distress experienced by patients/families because more appropriate questions can be asked and clearer information can be provided.

Such information will be especially valuable in situations when surrogates have to make decisions on behalf of another. Asking a person to decide on behalf of another about feeding issues demands that they take on a considerable burden. Part of the burden is the acknowledgement that they, the caregiver, will now have a different role where they can no longer show love by feeding. This also impacts how the patient will be affected in terms of

culture, family role, religious experience, and even receiving medication in a way that is appropriate. This is perhaps unique in the world of clinical interventions.

Acknowledging the role of food and feeding in the human experience may offer health care providers, patients and their families shared ground and a common language within which to frame the disease, a person's illness, and how to address care. This could begin or accelerate the development of rapport between everyone, and enhancing relationships impacts all aspects of a patient's world. Considering and acting on these issues would go a long way to easing the burden for all stakeholders, and ideally we need to address them in order to improve the situation of our patients and their families.

APPENDIX A: Basic Question Script

So I guess the best place to start would be just a very quick introduction – partly so I know how to pronounce your names and to get an idea of why you're here – so a little about your situation.

Now I'd like you to think of your own regular, everyday, normal life, your family and personal social lives.

Q1 Why do people eat and drink (*purpose*)?

Q2 What sort of situations do you feel food and drink are important in?

Q3 As you're preparing or serving a meal, what's important to you?

Now a slight change of direction: I'd like you to put your professional hat on and think about your work with patients.

Q4 When you hear the words *nutrition* and *hydration* what do they mean to you?

Q5 What's important to you in your role as a professional who cares for people with eating and drinking difficulties?

Q6 Are there differences between the meaning of "food and drink" in normal life, and the meaning of "nutrition and hydration" in health care settings? (What are these?) [If nothing then refer back to terms used by participants earlier in the discussion questions.]

Q7 Research shows us that altering the consistency of food/drink results in people eating less, and feeding tubes do not help everyone, yet we still recommend these things. Why do you think professionals do this?

Q8 In situations when we alter how people get food/drink how could we improve the experience of the patients and their caretakers?

Anything else you would like to add around the topics of health care and eating, drinking?

APPENDIX B: Human Research Protection Office (IRB) designation

From: IRB
Sent: Tuesday, December 08, 2015 2:49 PM
To: Leslie, P.
Subject: PI Notification: IRB determination

The IRB is requesting your assistance in helping us improve our service to the research community. Please take a few minutes and complete the Satisfaction Survey by clicking here.
Note: You can download a version of the approval letter without the survey link from the approved study workspace

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Paula Leslie PhD
From: IRB Office
Date: 12/8/2015
IRB#: PRO15060293
Subject: Health care professionals' perceptions of eating and drinking as a human experience.

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section

45 CFR 46.101(b)(2)

Please note the following information:

- Investigators should consult with the IRB whenever questions arise about whether planned changes to an exempt study might alter the exempt status. Use the "**Send Comments to IRB Staff**" link displayed on study workspace to request a review to ensure it continues to meet the exempt category.
- It is important to close your study when finished by using the "**Study Completed**" link displayed on the study workspace.
- Exempt studies will be archived after 3 years unless you choose to extend the study. If your study is archived, you can continue conducting research activities as the IRB has made the determination that your project met one of the required exempt categories. The only caveat is that no changes can be made to the application. If a change is needed, you will need to submit a NEW Exempt application.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX C: Gatekeeper invitation email

Health care providers' perceptions of eating and drinking as a human experience

Dear State Organization Member

We are forwarding this email from Dr Paula Leslie at the University of Pittsburgh who is requesting participants for a study she is conducting. Dr Leslie has not been provided with names of members/employees. If you are interested in finding out more about the study please contact her directly via email pleslie@pitt.edu, or telephone at the University of Pittsburgh 1-412-383-6748.

Message from Dr Leslie;

"We are conducting a short research study to explore what health care professionals think about eating and drinking and what it means to provide food for others. Data are emerging about how patients and families think about these things but there is little information on what health care professionals think about this topic. We are interested in hearing from professionals who work with people with swallowing impairments such as health care assistants, nurses, speech-language pathologists, and others who work directly with patients. This information will help us provide better clinical care in the future. The University of Pittsburgh IRB determined that this project was Exempt according to the regulations at 45 CFR 46 101(b)(2).

The study is using a focus group (small discussion group) approach which you are invited to participate in at the State Conference. The focus group will be held at x:xxpm on Friday xx and should last a maximum of 1.5 hours. Participation in the focus group is entirely voluntary and the participants' names will not be shared. Each participant will receive $20 as a token of our appreciation for your time. Light refreshments will be provided.

If you would like further information before you make a decision please contact Dr Leslie pleslie@pitt.edu.

I look forward to hearing from you."

Paula Leslie
PhD, FRCSLT (UK), CCC-SLP (USA)
Program Director: Doctor of Clinical Science (CScD), Professor, Communication Science and Disorders
Specialist Advisor (Swallowing Disorders) RCSLT
University of Pittsburgh, 6035 Forbes Tower, Pittsburgh, PA 15260
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APPENDIX D: Codebook

Table 3: Codebook

CODE	DEFINITION
ANXIETY	Relating to increased "anxiety" in patient/family/health care provider when terms nutrition/hydration are mentioned or being addressed, including embarrassment.
PATIENTCONTROL	Relating to patient wants, exerting their own authority, control (or lack) of a situation
RESPECT	Relating to respecting (or not) the patient, by a health care provider (self or other) because they are a patient or in a care facility, conscious of someone's dignity.
COMPROMISE_Fam	Relating to compromise with a family, giving some sort of professional ground to family wants or pressure
COMPROMISE_Pt	Relating to compromise with a patient
FACILITY_Change	Skilled nursing/hospital/etc. changing or should change environment/process to align institutional nutrition/hydration or eating/drinking to be more like home(y), normal.
CONFLICT_Inme	Conflict in myself about knowing one thing but doing another, or relating to a family member or patient differently
ETHICS	Mention of specific word
LEGAL	Relating to malpractice, fear of blame for bad thing happening to patient
MYPRAC	Professional practice: competence of self, assessment of patient, education of patient/family
MYPRAC_Change	Where health care provider has changed their practice with time and experience to be less stringent in following what was taught, general rules
MYPRAC_Hist	Reflecting on how external practice/knowledge was when first trained
MYPRAC_Respons	Aspects of professional practice: feeling responsible
SAFETY	Relating to issues such as is the food safe for a patient i.e. risk of choking, aspirating, sodium/special diet, adaptive devices to enable eating
CULTURE	Eating/drinking/nutrition/hydration relating to celebrations, cultural group identity
EXPECTATION	Expectations about how a food will be, that some food will be at an occasion
HISTORY	Relating to historical connections and transference across time (people,

	places)
PEOPLE	Eating/drinking/nutrition/hydration relating to self identity, family, individual people, communal
PREP_Other	Importance to the preparer that they please others, transfer care, love, share something
PREP_Self	Importance to the preparer that they've done a good job, healthy, looks nice, validation
EATCOMPNUTRI_Diff	Eating/drinking different to nutrition/hydration
EATCOMPNUTRI_Same	Eating/drinking same as nutrition/hydration
NUTRISPECIAL	Issues that make nutrition/hydration concerns different to other medical concerns
ECONOMIC	Cost saving practices or financial incentive
OTHERPROF	Relating to working with or educating other professionals
OTHERPROF_Conf	Relating to conflict in working with other professionals, case management
OTHERPROF_Cover	Relating to health care provider feeling responsibility to do something another professional should have done e.g. SLP explain something a doctor should have
PLEASURE	Eating/drinking/nutrition/hydration for pleasure, fun
PLEASURE_Neg	Eating/drinking/nutrition/hydration for boredom, stress, habit
WHYED_Health	Eating/drinking/nutrition/hydration contributing to health in general
WHYED_Health_Spec	Eating/drinking/nutrition/hydration contributing to health specifics, physiology, fuel, medications working, hunger
WHYED_Health_Survive	Eating/drinking/nutrition/hydration contributing to survival, life sustaining, critical health
OTHER	*Things that did not map to any themes.*
END	*Final comments not coded elsewhere*

Table 4: Themes color key

Patient experience
Improving things
Reasons for practice patterns
The meanings of food and feeding
Nutrition/hydration vs. food/drink
Economic concerns
Professional collaboration
Why we eat and drink – health and life

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